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SOCIAL CATEGORIES AND HEALTH CARE OUTCOMES: AFRICAN AMERICAN WOMEN AND HIV SURVIVAL IN THE URBAN SOUTH

Alyson J. O'Daniel
University of Kentucky, alyson_anthony@hotmail.com

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ABSTRACT OF DISSERTATION

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SOCIAL CATEGORIES AND HEALTH CARE OUTCOMES: AFRICAN
AMERICAN WOMEN AND HIV SURVIVAL IN THE URBAN SOUTH

ABSTRACT OF DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Arts and Sciences at the University of Kentucky

By

Alyson J. O'Daniel

Lexington, Kentucky

Director: Dr. Mary K. Anglin, Associate Professor of Anthropology

Lexington, Kentucky

2010

ABSTRACT OF DISSERTATION

SOCIAL CATEGORIES AND HEALTH CARE OUTCOMES: AFRICAN
AMERICAN WOMEN AND HIV SURVIVAL IN THE URBAN SOUTH

This ethnographic research examines the daily life and institutional conditions under which low-income Black women in urban North Carolina perceived and attended to HIV health-related needs. I focus specifically on the interplay among women's living conditions, programmatic service needs, and their strategies for navigating the local system of care to explore and refine the categorical label "low income." I found that there were significant differences among study participants in terms of their monthly incomes and financial resources, housing quality and status, and personal experiences with incarceration and substance abuse. The economic differences among women translated into social differences within the context of federally-funded AIDS care programs. Social differences were realized as the differential ability to transform programmatic services enrollment into beneficial social networks. Ultimately, financially stable women were better positioned than their more economically vulnerable counterparts to reap the economic and social benefits of programmatic services eligibility and enrollment. It is in this context that I explore federally-funded AIDS care services as one social field through which processes of class unfold and articulate with processes of race and gender.

KEYWORDS: HIV/AIDS, Health Care, Intersectionality, Programmatic services

Alyson J. O'Daniel
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Student's Signature

March 22, 2008
_____
Date

SOCIAL CATEGORIES AND HEALTH CARE OUTCOMES: AFRICAN
AMERICAN WOMEN AND HIV SURVIVAL IN THE URBAN SOUTH

By

Alyson J. O'Daniel

Dr. Mary K. Anglin
_____
Director of Dissertation

Dr. Richard Jefferies
_____
Director of Graduate Studies

March 22, 2010
_____

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their lives and experiences warrants my most profound gratitude. I will never forget the warmth and enthusiasm with which you all received me. For the women whose life experiences provided the backbone of this dissertation, I cannot express how grateful I am to have been given the opportunity to witness the strength and courage you demonstrate. For the care providers who serve as the heart and soul of Health Partnership, your commitment to serving the local community inspires me. I extend my most sincere "thank you" to all of you.

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On a sunny Monday afternoon, I sat in Health Partnership's parking lot talking with Kareese[i] about her latest personal victory along the road of substance abuse recovery. It was September of 2008 and I was close to finishing sixteen months of fieldwork in North Carolina. I had been exploring the role of federally-funded health care programs in low-income women's experiences of survival with HIV disease. My research was designed to speak to the ways in which social categories such as race, class, and gender are made meaningful under conditions of health. However, I had months before resigned myself to the possibility that the dissertation would focus on themes familiar to urban poverty researchers such as bureaucracy, impoverishment, and institutional neglect. I could not yet see what women had been telling me and showing me throughout the research process. My conversation with Kareese on that day, however, helped me to put women's experiences and stories of survival into sharper focus.

Eleven months prior to this conversation, Kareese volunteered to participate in this research about survival with HIV disease. Kareese and I had come to know each other quite well. We had shared much laughter and many afternoon conversations about the system of HIV care, her personal life circumstances, and her health. On this particular afternoon, Kareese rushed into the lobby of the organization and promptly asked me if we could go outside to talk. I knew something was wrong because our usual routine was to visit in the lobby for a while with anyone who was around and willing to chat. We would inevitably move outside after thirty minutes or so to smoke a cigarette and talk privately. Chatting inside was an important part of our routine because it gave Kareese a chance to greet everyone and to catch her breath following the bus trip to the organization.

For several months Kareese and I had maintained our informal agreement and this itinerary of sorts. We always met on food pantry shopping day to discuss whatever details were happening in her life and to make any plans we felt necessary for meeting outside of Health Partnership. Food pantry day was the best day for Kareese to visit with me because the distraction of our conversation helped to pass the time while she waited

her turn to be served. This afternoon was different, however, and Kareese's exaggerated hand gestures and quickened breath let me know that she was on edge. She was in no mood to wait among a crowd for her turn for food pantry. As we walked outside and sat down on the pavement, Kareese told me that she had just been released from an in-patient psychiatric facility. In her estimation, the pressures of her life "just got to be too much." She admitted herself to the facility rather than take the chance that she might hurt herself in some way.

Kareese had just recently achieved forty-five days sober. This was not her first attempt at recovery, but was thus far her longest continuous stint of sobriety. She had endured years of crack addiction and the emotional ups and downs that can accompany chemical dependency. Kareese's HIV positive diagnosis in 2000 at first intensified her cravings to use. Before diagnosis Kareese had only occasionally smoked crack in social settings, but she was now struggling with an almost daily habit. Since seeking care for her diagnosis, however, she began to fear the potentially lethal combination of crack use and HIV infection. Her doctor had long discussed with her that smoking crack could potentially speed up replication of the HIV virus in her body. Yet, the fear of smoking crack in the face of HIV disease had proven time and again as an inadequate match for powerful cravings associated with withdrawal. Throughout this research, Kareese and I often discussed the stresses and strains in her life that made it challenging for her to abstain from illicit drug use. Principle among these stresses and strains were the difficult conditions of her daily life.

Like many women living in poverty, Kareese made what she described as "tough choices" based on limited options. She shared an apartment with her estranged husband who often smoked crack at home and teased Kareese about her physical appearance. Separately they struggled to find stable employment, to keep their refrigerator stocked, and to keep individual bills paid. Together, they struggled to afford a small apartment in a rental property complex adjacent to one of the most notoriously dangerous housing projects in town. Drive-by shootings posed a serious threat to residents in the surrounding area. Kareese had been herself grazed by a stray bullet six months earlier while sitting on her porch playing cards. Kareese's feeling that "there is no quiet days in

my neighborhood" was reinforced by the drug dealers who would knock on her door offering a "free taste" whenever she tried to stop smoking crack.

On the Friday afternoon before our private talk in the parking lot, all of these hardships raced through Kareese's mind as she listened to the doctor explain to her that the stomach cancer with which she had long ago struggled had likely returned. More testing needed to be done before they would know for sure. Kareese would have to wait until Monday for the testing to begin. Monday, it seemed, was too far off for Kareese. She described how all she could think of doing was buying a crack rock to numb her mind. She resisted the urge and instead returned home.

Once at home, Kareese feared that she could not rely on family to prevent what seemed like an inevitable emotional breakdown or recovery relapse. Instead, Kareese relied on her institutional knowledge and skills. She checked herself into the psychiatric ward of a local hospital. Upon her release, she came to Health Partnership to make a plan for the upcoming weeks and to feel supported by people who understood the challenges of living life with HIV disease.

Despite her financial hardships and the discomforting conditions of her neighborhood, Kareese resisted any feelings of self-pity or regret. She, instead, concentrated on building a future where she was financially comfortable, emotionally stable, and physically healthy. Like all of the women who participated in this research project, Kareese turned to Health Partnership as an integral part of her strategies for survival with HIV disease. Health Partnership, as I learned throughout this research project, was cast by women as central to their strategies for health and household maintenance. Thus while conditions of bureaucracy and institutional neglect were certainly part of many women's experiences of survival, they were but one part of a "bigger picture." That Kareese had turned to public service institutions in her time of need, rather than turning to family or friends, was significant. That Kareese maintained sobriety over that weekend was also significant. Health Partnership, to which she then turned for continued support, represented a central link in the institutional network she had been cultivating for years.

Health Partnership is a federally-funded AIDS service organization in Midway, North Carolina[ii]. It served as the principal service location through which Midway's HIV

positive women gained access to health-related resources, material assistance, and, ultimately the means for social network expansion. At the time of this research, Health Partnership was responding to the 2006 re-authorization of the Ryan White CARE Act, formally known as the Treatment Modernization Act[iii]. In compliance with new federal regulations concerning oversight and definitions of health care in this context, Health Partnership was in the midst of re-organizing its services and eligibility criteria. In the context of rapid change and undefined terminology in new Ryan White legislation, Health Partnership paradoxically served as a medium through which social divisions based in processes of race, class, and gender were transformed into differential chances among women for daily life stability and for health.

Despite that all of the women in this study are considered under federal guidelines as categorically low income, I here examine the diversity among low-income Black women living with HIV disease. This diversity is made strikingly clear when HIV/AIDS care services are examined in relation to women's life strategies and experiences rather than in relation to service provision policy, procedure, and protocol mandates. Such a perspective casts light on the different and sometimes unintended uses to which social programs may be put by women under varying conditions of health and economics.

Within the context of public health care and related institutions, this dissertation is an examination of how low-income HIV positive Black women experience and perceive HIV disease in relation to their social positions in a deeply stratified society. I explore the material conditions of survival with HIV disease in relation to the personal and institutional conditions that women define as important for their health. I contextualize these experiences in the broader context of neoliberal economic reform and its articulation with historically-driven processes of social and economic disenfranchisement.

Organization of the Dissertation

One of the goals of this dissertation is to contribute to the medical anthropological literature concerning the role of social categories in structuring experiences of health. As most anthropological scholars must concede, I draw from a variety of academic

disciplines and theoretical foci for highlighting the social processes structuring survival with HIV disease. The complex nature of experiences of health and survival requires a theoretical framework capable of speaking to the interactions among the structural conditions of society, lived experiences, social action, performance, and transformation. In Chapter two, I lay out the theoretical foundations for this research. I position this research at the intersection among three broader literatures. I focus in particular on political economic medical anthropology, feminist medical anthropology, and Black feminist theory. Taken together, these literatures provide a framework for thinking through the social processes and conditions associated with novel configurations of inequality and health vulnerability.

Chapter three provides for the institutional context of women's lives. I describe the structure and content of federally-funded AIDS care programs in Midway. In one instance I explore the HIV/AIDS system of care as a series of programs, policies, and procedures aimed at increasing access to and retention in health care and supportive services. I focus in particular on federal programs and policies as implemented and administered by Health Partnership staff. I further situate Health Partnership programs and procedure with respect to other social service programs that are available to low-income women. Although programs such as welfare, Medicaid, and Vocational Rehabilitation are administratively viewed as discrete service entities and not under the purview of Ryan White legislation, they were an important part of the institutional fabric of women's lives.

After describing the policies and programs comprising the local institutional context, I discuss an alternative strategy for thinking through how social service institutions are used by women in their daily lives. I lay the foundation for theorizing "the system" as a web of social relationships that is defined, maintained, and transformed through the interactions among women and providers of care. The ways in which women utilize the system for their daily life strategies and health needs is paramount. Thus while policies and programs are mandated and maintained by state funds and agents of the state, the content and function of AIDS care is contingent upon the skills and resources women bring to bear in their experiences of programmatic services reception. I emphasize an understanding of public health care institutions as a medium through which

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women rebuild otherwise fractured and over-stressed social networks. This perspective is based on a notion I call "social network surrogacy." This notion emphasizes how, in contexts of severe and chronic deprivation, social service institutions can provide a means for building and/or strengthening social relationships that are conducive to economic stability.

After exploring the institutional context of women's lives, I explore the differences among women who volunteered to participate in this research. Chapter Four uses the insights of Black feminist theory to explore the various social contexts through which women grappled with health and health care. The women in this study experienced similar social positions within the shared contexts of local and national political economies. In the shared context of local HIV health care, however, "one size did not fit all." I explore the notions of "class processes" (Gibson-Graham 1996; Gibson-Graham et al. 2000), social capital (Bourdieu 1986), and biopower (Foucault 1978) for thinking through women's relative social positions within a local political economy of care and support services.

In Chapter Five I explore the material differences among women. Here I provide an ethnographic examination of women's daily life circumstances. Drawn from women's experiences at home, with their families, in their neighborhoods, among friends, and in the public spaces they frequent, this chapter examines in depth living conditions, health needs, and strategies for household maintenance. I examine women's social and economic positions vis-à-vis social processes associated with housing status and quality, income generation, and personal social networks. This approach lays bare the articulations among class processes, conditions of social and material (in)stability, and health needs.

Chapter six further explores the contexts of women's daily lives to consider the relationships among programmatic services and experiences of health. This chapter provides an analysis of women's relationships to the structure and conditions of the system of care. I elucidate the ways in which women's abilities to "personalize" their institutional networks matters for material security and the definition and satisfaction of health needs. It is here where I consider the ways in which "differences" among women matter in the context of federally funded services. I take up the notion of social network

surrogacy to understand the impact of difference upon women's daily life conditions, and focus specifically on women's abilities to transform institutional relationships into material advantage.

Chapter Seven explores women's perceptions of HIV disease. This chapter spotlights perceptions of HIV disease as a medium through which women express how diagnostic technologies of HIV-related health and illness articulate with social conditions and experiences. I specifically focus on how women's material circumstances and social positions within the system of care shape how they understand and talk about HIV disease and survival. I argue that women's most immediate daily life concerns provide a perceptual filter through which women come to terms with the impact of HIV disease on their lives. I assert that the differences among women with respect to their perceptions concerning HIV disease can be used signposts for implementing support programs that are responsive to the various contexts in which categorically low-income HIV positive Black women negotiate survival.

In each chapter I endeavor to explore the range of possibilities met with constraint and experienced among women in the particular settings of social service institutions, home, neighborhood, and family. It is my intention to illuminate the complexity of women's experiences while maintaining focus on social processes through which survival with HIV disease can be understood. In this context, Health Partnership services and protocol are not simply part of the background, as I had originally imagined for this ethnography; they are foundational to the ways in which women navigate the intersecting terrains of health and daily life.

CHAPTER TWO:
THEORETICAL FRAMEWORK AND RESEARCH METHODS

There is no all-encompassing theory with which to explore lived experiences of HIV disease in the contemporary United States. As such, this dissertation resides at the intersections among various scholarly literatures and theoretical traditions within anthropology. As an inter-disciplinary and holistic research perspective, anthropology is particularly well-suited to creatively answering questions concerning the public health agenda (Inhorn 2006) as well as how experiences of health and biomedicine reflect social, political, and economic relations (Whiteford 1996). Here I draw from the various literatures of political economic medical anthropology, feminist anthropology, and Black feminist theory to consider how lived experiences of HIV disease are shaped by the conditions of and participation in federal social programs.

Conceiving the Structural Conditions of Health and Survival

In political economic medical anthropology (PEMA), health and illness are understood as multi-factorial, historically-based, and systemically-produced processes (Dressler 2001; Mwaria 2001; Nguyen and Peschard 2003). HIV disease is no exception (Farmer 1996; Hyde 2007; Maskovsky 2005; Singer 1995; Susser and Stein 2000). Recognizing that health is a political issue (Cohen 1999; Collins 2001; Doyal 1995; Kim et al. 2000; Morgen 2002; Navarro 1984; Roberts 1997; Schneider and Stoller 1995; Singer 1995), I conceptualize the HIV/AIDS epidemic as a nexus through which to understand social change, power relations, and lived experiences of inequality.

Anthropologists have conceptualized the epidemic among women of color in terms of political and economic disenfranchisement (Cohen 1999; Farmer 1999; Singer 1995). Structural reform and pervasive racial and gender stereotypes present in policy discourses have positioned poor African American women as being well-suited for low-skill work (Davis 2004; Piven 2001). The reconstitution of poor women of color as low-wage workers articulates with a growth in female-headed families in Black communities (Goode 2002; Hays 2003; Mullings 2001; Seccombe 1998; Susser 1993, 1996; Starrels et al. 1994), a decline in employment opportunities, and a decline in wages for those who

are employed (Piven 1998 and 2001). Poverty complicates women's abilities to avoid HIV infection by hindering financial stability, health care access, and autonomy (Carovano 1991; Gollub 1999).

Unemployment, underemployment, and neighborhood dilapidation operate to distribute risk along social divisions (Singer 1995). Women must weigh the risk of HIV infection against other possibilities such as homelessness and loss of essential income (Connors 1996:93). Sex work, condom-less sex, and needle sharing are strategies for attaining money, resources, emotional support, and physical protection in contexts of deprivation (Connors 1992; Fullilove et al. 1990; Koester and Schwarz 1993; Sobo 1995). As primary care-givers and wage earners for their families (Piven 2001) within the context of diminished earning opportunities (Bourgois 1996; Sassen 1996) and the government divestment of public services (Newman 2001; Susser 1996), African American women are, through their economic vulnerability, at increased risk for infection (Farmer 1996:23; Lane et al. 2004; Worth 1989).

Overall, the literature makes clear that in a context wherein employment opportunities and basic resources are scarce and inextricably tied to racial and gender discrimination (Goode and Maskovsky 2001; Mullings 2001), women will continue to have to choose between their more short-term survival needs and their long-term health. As Connors (1992) points out, HIV/AIDS among poor women is a long-term survival issue rather than an immediate concern. The risk of HIV becomes "just another burden" with which poor women of color must cope. In light of these interconnections between HIV infection and economic conditions, I draw from scholars who characterize disease as the embodiment of social inequality (see for example Becker 2004; Harrison 1994; Kim et al. 2000) to focus on how relationships of gender, race, and class culminate in unequal access to resources and poor health outcomes among HIV positive African American women.

Over the last few decades, much political economic medical anthropological research has focused on the role of accelerating economic globalization in the production and maintenance of health disparities and poor health outcomes among poor and disenfranchised populations of women (Baer et al. 1997; Castro and Singer 2004; Doyal 1995; Kim et al. 2000). Neoliberalism has emerged in this context as a key concept for

conceiving of the structural conditions under which women navigate HIV health and survival.

Following Goode and Maskovsky (2001:8), I conceptualize neoliberalism, in part, as the resurgence of classic liberalism's faith in the economic, social, and moral attributes of unhindered and unregulated markets. This definition makes use of "neoliberalism" as a heuristic device for interpreting state policies and practices. The neoliberal state is here theorized to function as a mechanism for upholding the free market as a principle means for economic growth and social welfare (Hawkesworth 2006; Kingfisher and Goldsmith 2001; Lehman and Danziger 2004). A "free market" is realized through policies aimed at market deregulation, technological innovation, and competition. Such conditions favor the creation of a flexible labor force and measures aimed at corporate downsizing and state disinvestment in public services (Gershman and Irwin 2000; Good and Maskovsky 2001). It is in this context that the development and implementation of local social programs can be understood.

This analysis further draws from Harvey's (2007:19) notion that the creation and management of a "global free market" system functions to restore power to a class of economic elites. He argues that the impact of novel entrepreneurial possibilities and the restructuring of international trade relations impacts upon processes of class formation. In effect, a narrowly defined capitalist class emerges alongside the consolidated power of corporations. Neoliberal ideology emerges in the service of power as a mechanism for the inculcation of market ideals beneficial to elites. Neoliberalism is thus here further understood as a series of policies and procedures aimed at structuring relations of class privilege and subordination.

Finally, this research maintains a commitment to the historical delineation of structures of inequality and the reproduction and maintenance of such structures through time (Baer et al. 1997; Kim et al. 2000; Morgan 1987; Morsy 1996 and 1988). Social, political, and economic systems of inequality are here conceptualized as historically-based and interconnected processes that shape the conditions of HIV infection and survival in the contemporary US. It is in this way that women's stories and experiences of survival provide much more than a lens onto the present; their life circumstances reflect the social, political, and economic conditions of decades past. The theoretical

framework of this dissertation draws from the past as much it seeks to theorize present conditions. I assert that the legacies of sexism, slavery, and segregation in the US continue to be visible in contemporary relations of disparity and neglect (Brodkin 2000; Mullings 1997; Quadagno 1994).

Gender and Processes of Health and Health Care

This analysis also draws from the insights of feminist medical anthropology. Feminist anthropological approaches to human health explicitly consider how gender relations and gendered power imbalances affect processes of health and health care (Ginsburg and Rapp 1995). While researchers find that global inequalities in wealth and income, environmental degradation, and barriers of race and class may similarly affect men and women, there are gender specific obstacles to health (Doyal 1995). Gender specific obstacles to health and health care in this setting can include conditions such as unequal burdens of domestic labor (Mullings 1997), unequal access to household resources (Croll 2000; Van Hollen 2003; Inhorn 1996), and constraints on women to determine their own sexuality and procreativity (Colen 1995; di Leonardo 1991; Doyal 1995).

Central to the feminist literature concerning HIV health is the recognition that Black women have historically filled the gap between their communities' HIV-related needs and the available services. As invisible caregivers (Schiller 1993), pragmatic strategists (Battle 1997; Williams 2003), advocates (Berger 2004), and organization builders (Cohen 1999; Stoller 1998), Black women have been conceived of as "institutional allies" and community strategists in the provision of care, even as they too struggle with HIV (Schiller 1993). In this perspective, Black women's strategies and care networks are aimed at alleviating poverty and institutional neglect in resource poor settings (Cohen 1999). Black women have been fruitfully understood as strategists on behalf of others, minimizing their own needs for the sake of their loved ones and communities. I draw from these studies to consider women's experiences with the *reception* of care as a process of gender and thus as a structural process.

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The stories women shared with me concerning their experiences of HIV disease also speak directly to the ways in which health and health care can be depoliticized by the hegemonic perspectives of biomedicine (Inhorn 2006 and 1996; Morgen 2002; Pearce 1995) and market-based health care (Browner and Press 1995). Following Morgen (2002), I consider how public health and social welfare institutions can provide one locus for simultaneous resistance to and conformance with normalizing logics of biomedical science and market-based medicine. This approach amplifies women's capacities to interpret and act upon broad scale forces (Morsy 1995 and Das 1995) such as the racism, classism, and sexism that are often bolstered by neoliberal policy and ideology.

Structure and Agency: Theorizing the Dynamics of Care through Lived Experience

In many academic circles, the macroanalytic perspective touted by PEMA scholars is critiqued for what Ortner (1984:143) refers to as the inability of political economic analyses to sustain focus on people "doing real things" (see also Dressler 2001 and Morgan 1987). She argues that people are not passive "reactors" to and "enactors" of a system. Rather, people are active social agents in constructing their lives and life chances. Similarly, Dressler (2001) partitions medical anthropological scholarship into two categories: that which is concerned with the meaning of events and circumstances and that which is concerned with the articulations among various elements of society (see also Morgan 1987).

Conversely, anthropologists (Baker 1998; Di Leonardo 1998; Wolf 1982) have explored the scholarly implications of analyses based in notions of a "cultural other" that do not take into account the structural dynamics producing "difference" (Di Leonardo 1988; Narayan 1997). Too often in early HIV/AIDS research, a dark skinned, sexual, and cultural "other" stood in place of the complex and dynamic experiences of women at risk for HIV infection and AIDS-related mortality (Cohen 1999; Treichler 1999). I attend to these popular stereotypes and critics of these stereotypes by drawing from the theoretical insights of medical anthropologists who focus on how macro-level structural processes shape and are shaped by the micro-level contexts of lived experience (see for example Bourgois 1996; Mullings and Wali 2001; Petryna 2002; Scheper Hughes 1992; Lock

2001). Such analyses privilege neither processes of capitalism as the principal unit of analysis nor the "subjective content" of illness (Morgan 1987:135). Instead, such work incorporates theories concerning the social practices of research participants *and* the structural constraints they face.

By centering lived experiences of inequality in the production of anthropological research analyses, Black feminist theorists claims a particular consciousness concerning the dynamics between structure and lived experience. Race, for example, is defined as a social construction that is experienced through a structural reality that has associated social, economic, and political ramifications (McClaurin 2001:5). Structural realities associated with race can only be fully grasped from the standpoint of the "raced" individual or group. From the perspective of standpoint theory, the Black feminist intellectual tradition [iv]seeks to locate structural processes of race and class as central to the study of gendered experiences (Collins 2001). By doing so, lived experiences of Black women are validated from the outset as a fruitful site for the production of new concepts, theories, methodologies, and ideas (Mupotsa 2006).

Collins (1990), for example, points out how Black women's lived experiences as "bloodmothers, othermothers, and community othermothers" opens up a conceptual space for theorizing discourses of the heterosexual nuclear family as emergent from specific race and class formations. This conceptual space illuminates how the performance of various types of "mother work" ensures social reproduction under otherwise hostile social and political conditions. By re-defining notions of family and care work with reference to lived experiences of Black mothers and other mothers, Collins subverts normative notions of family and individualism.

I further draw from intersectionality theory (see for example Mullings and Schulz 2006) to consider the interactive and multiplicative effects of race, class, and gender for women's life circumstances. Intersectionality theory is the fundamental basis for rejecting analyses that privilege one axis of social difference, such as gender, for explanations of the sources of oppression or identity (Bolles 2001; Collins 1990; Ebron 2001). Intersectionality theory instead explores the complex intersections of gender, race, and class to make more explicit the particular ways in which Black women's lives are mediated by the confluence of structural forces (Weber 2006; Zambrana and Dill

2006:196). Thus race, class, and gender are consistently viewed under this framework as simultaneously oppressive social processes, combining in various ways that are always historical and contextual (Bolles 2001:34; Caldwell, Guthrie, Jackson 2006:164). Contrary to more traditional approaches to social difference, Black feminist theorists assert that the mutual construction of social categories makes it difficult to measure the unique contribution of any single one. Social categories, in other words, are here conceptualized as fluid, shifting group relations that persist, albeit in different forms and through different vehicles, through time and space (Weber 2006:34).

Taken together, the theoretical underpinnings of this research draw attention to the ways in which race, class, and gender operate as dialectical processes shaping conditions and experiences of health (Barbee 1993; Becker 2004; Breen 2002; Mullings 2002; Mullings and Schulz 2006; Nguyen and Peschard 2003). This perspective spotlights that history, power, agency, and political economy converge in both the production and experience of social difference (Mullings and Schulz 2006:5). Intersectionality theory complements the historically-based focus of political economic medical anthropology, elucidating how race, class, and gender intersect to form structural positions from which women experience conditions circumscribing health. Also, by highlighting the interactive, multiplicative (Mullings and Wali 2002), locally contingent (Susser and Stein 2000), and socially constructed (Collins 2001) nature of Black women's social positions this theoretical framework provides a lens onto experiential differences among HIV positive Black women to explore the variability obscured by the categorical label "low income."

Methodological Considerations

The data collection methods employed here are shaped by the values and goals of feminist and Black feminist theory. The decision to limit this research to the experiences of women was a politically-conscious decision that speaks to the feminist goal of inserting women into the social and historical record (Nielsen 1990). The methods discussed below are informed by feminist theory and practice as a means of focusing data collection and interpretation on processes of health that the women in this study

identified as important in their personal life contexts and communities. In further accordance with the foundational tenets of Black feminist theory, this ethnographic methodology seeks to de-center White mainstream perspectives on survival with HIV disease by centering this work on the lives and experiences of Black women (McLaurin 2001).

Feminist and Black feminist research methods are built upon both critical and interpretive systems of inquiry (McLaurin 2001; Nielsen 1990:7). Considering that the driving force behind feminist research is to call attention to gender-based oppression, feminist methods are explicitly designed to reject "value neutrality" in favor of illuminating unequal power relations. Black feminist methodologies refine this feminist driving force to further amplify how women experience gendered power dynamics in relation to the power-laden processes of race and class. Such an approach recognizes the ways in which "traditional" social science research models represent a White male standpoint (Collins 1990:203), meaning that knowledge concerning Black women's lives has been either absent or constructed from the perspective of White men. Black feminist research seeks to counter this perspective by centering the lives of Black women in the production of knowledge (McLaurin 2001).

Finally, feminist methods are unapologetically anti-positivist (Barrett 1996:164) and distinctly concerned with the lived experience of inequality. This approach to social research draws from subjective experiences of oppression, notions of empathy, and the facilitation of dialogue between the researcher and the research participant. The research design described below was planned and implemented as an integration of the feminist philosophy of data collection and analysis and more traditional anthropological fieldwork techniques.

Situating the Researcher

The decision to conduct research among HIV positive Black women in North Carolina was based upon the epidemiological course of the epidemic and the abundance of federally-funded health care programs in Midway, NC. While such justifications made enough academic sense, they meant that I entered into the field knowing virtually none of

the major players who would eventually define this ethnographic analysis. I was, as many new fieldworkers similarly experience, an un-known entity in Midway's public health care circuit and local neighborhoods.

I conducted preliminary research the summer prior to entering the field, but changes in Ryan White legislation had dramatically changed the landscape and membership of the community. Several of the key contacts I had previously established were no longer in residence. I thus spent the first four months of this sixteen month project positioning myself to meet the current key players in the HIV service provider community and client population. I defined "key players" as persons who had long-term experience with the local system of AIDS care and related services. Key players included particular service providers from Health Partnership, long-term HIV disease survivors, and members of the local HIV consortium. I sought their knowledge concerning the structure and history of the local HIV "community." Relationship building with key participants, as I soon learned, was fraught with tension. It was months after I entered the field before I could begin to think through my own social position. In the end I recognize my own positionality as a negotiated and complex set of relationships that were made and re-made in various fieldwork contexts.

Many anthropologists have discussed as disquieting the ways in which they are "known" in the field in relation to research participants. In some cases, participants seem to emphasize that the anthropologist is a researcher and so may adopt particular kinds of relationship strategies for fulfilling their roles as research participants. Bourgois (1996:46-47), for example, discusses how the participants in his study would often request that their most shocking experiences be included in his "best seller." Meyerhoff (1980) was placed in an uncomfortable role as researcher/daughter-figure within the context of a neighborhood senior center. My experience as a person performing research was no exception to the methodological record. My relationships with research participants were certainly complicated and sometimes frustrating. Tension and ambiguity perhaps best characterize many of my fieldwork relationships. However, in my estimation, realizing the tension and ambiguity of these relationships is more productive than disquieting. It is within these tensions that the politics of research performance are laid bare.

It was as a young, White, female researcher that I entered into the field. And, it was as a young, White, female researcher that I collected data and exited the field. I wish that I could discuss how I became an honorary "insider" in Midway's HIV positive community. I secretly hoped that I would somehow manage to elide the boundaries of race and class to find a space outside of power where there would be true sharing between the researcher and the researched. I knew this was not really possible. Yet, while in the field I often thought about how I could communicate my feelings of solidarity (sometimes real, sometimes imagined) with the women with whom I worked. I did know, however, that such a display could produce resentment, discomfort, and quite possibly laughter. While I tried very hard to "hear" what women were telling me, I knew that my own position of privilege shot through every question I asked, every prompt I offered, and every interpretation I made. I became conscious of the "White metaphor" I might be reinforcing as a White researcher conducting this particular study with Black participants.

With that recognition, I became more comfortable with the varying ways that I became "knowable" in the field. In some contexts I was the researcher asking questions, listening intently, making clarifications, and taking notes. This role was always circumscribed by my Whiteness, my age, my economic background, and my gender. Women would sometimes assume that I was unfamiliar with historical circumstances such as AFDC policies because of my age and my presumed economic background. Women sometimes also assumed that I would be uncomfortable in their homes and neighborhoods. As one research participant stated in a phone call to confirm our later interview appointment, "…you're like a moving target in the 'hood. Call me when you get here and I'll walk you from your car." Truth be told, sometimes I did feel out of place in women's homes and neighborhoods. As I performed and sometimes fumbled through my roles as a researcher, women were gracious and patient community hosts— even if they had an occasional laugh at my expense.

In informal contexts, I was a young White woman that had not yet learned how to respond to women's banter. For example, I was called "Similac" (a commercial brand of infant formula) by two research participants until months later when I responded by calling them "Metamucil" and "Ben-Gay." With much laughter and a hug, "Metamucil"

responded that Midway was "toughening" me. This short dialogue was a pivotal moment in this set of relationships, but it did not redefine who I was in the field. Indeed throughout the study, some women seemed eager to put me in my place as an outsider by calling me such names as "White girl," "skinny ass," and "little momma." The name-calling, I still believe, was not meant to hurt my feelings. It performed a much more important function; it served as a reminder that the privilege of studying women's daily life contexts was contingent upon participants' good will, patience, and willingness to engage with anthropological research methods.

Throughout the course of this research, many women recognized that my privilege could be useful to them in a service professional context. Women often asked me to speak on their behalf to social service professionals. Thus at times I performed the role of intermediary in the public health care system. Privilege operated in this context in strange ways. Social service professionals accepted without question when I vouched for appointments so that women could get bus tickets. I also confirmed household crises so women could get extra food from the food pantry with no questions. In this capacity I helped women reschedule their missed appointments in a timely manner and was even asked to ensure one woman's timely admission to one of the local hospitals. I was always eager to help in this way, but often fretted over what my role as "voucher" potentially said about the dynamics between social service providers and their clients. In some cases, I believe service providers felt that my research relationships with clients validated women's claims. I was, it seemed, "in the know" because I spent time with women in their homes and neighborhoods. My status as a university-trained professional lent a kind of credibility to the support I offered women. In other cases, it is possible that service providers felt self-conscious about seeming uncompassionate or inflexible in the context of this research. My status as a university-trained professional was perhaps sometimes understood by care providers as a kind of surveillance. These various roles that I engaged in the field enhanced the original research design by providing me with various positions from which to engage with women's life circumstances.

Research Design and Methodology

As is characteristic of many ethnographic research projects, I collected the majority of the data through participant-observation and semi-structured interviews. These methods were supplemented with informal face-to-face conversations, telephone calls, follow-up visits with participants, and community involvement.

<u>*Participant-Observation*</u>

I began this research in November 2007 as a participant-observer at Health Partnership, Midway's local HIV service coalition. I had learned of Health Partnership during the preliminary research phase and was able to re-establish permission to conduct part of this research at their offices located in Midway's downtown neighborhood. This setting was an ideal location for learning about federally funded HIV health care as well as for meeting service providers and members of the local HIV positive population. As the largest community-based recipient of Part B Ryan White funds, Health Partnership had recently expanded their service programs to include: emergency assistance, food pantry, risk reduction counseling, case management, nutritional screening, medical case management, pastoral care, and STD testing services. My arrival had fortuitously marked the beginning of a new era in the local Ryan White care continuum.

Over the course of eleven months, I went to the organization at least twice weekly. In the early stages of this project, I conducted participant observation at the organization four to five days a week. I was eager to meet potential research participants. I was also eager to be a part of the dramatic growth Health Partnership was just beginning to experience. Established service "veterans" as well as new employees quickly put me to work. I offered a hand for those setting up new offices or creating and distributing fliers about new care programs. Throughout the course of this study, I also helped as a food pantry volunteer by assisting the nutritionist with food bank shopping and the manual labor associated with it.

Health Partnership gave me a home where I could begin meeting HIV positive women and their loved ones. I became "knowable" to women through the organization as a researcher, a volunteer, and a person. The organization's waiting area and client

lounge hosted most of my first acquaintances with research participants and many subsequent conversations. Many of the women with whom I worked were not employed or were sporadically employed. Health Partnership, in these contexts, was a regular "stop over" for women searching for ways to combat boredom, anxiety, addiction cravings, or loneliness. The informal atmosphere maintained by most staff members translated into a community space where organization clients could stop in unannounced for companionship, advice, and entertainment. I spent many an afternoon sitting in the parking lot of the organization smoking cigarettes, laughing, and talking with the women in this study.

In some cases, women would prefer to drive around while we chatted. We would leave Health Partnership for an hour or so and drive around town talking about the details of their lives. I learned about the public places women frequented, the various neighborhoods in which they had lived, and the challenges they faced for meeting their basic needs. In three cases, these afternoon drives culminated in women giving me a "tour" of the various locations around town where they had encountered physical violence. It was through these excursions that I really began to learn how women make sense of their neighborhoods and the city.

A few months into the project, I began conducting regular participant observation with 6 women. This was significant because our meetings had moved from Health Partnership into their homes and other such daily life spaces. This group of women ended up reflecting the diversity of the interview sample with respect to socioeconomic context and length of time since diagnosis. We spent countless hours running errands, "window shopping," observing and discussing neighborhood dynamics, and generally just "hanging out" in women's homes. I sporadically conducted participant observation outside of Health Partnership with an additional eleven women. These opportunities usually arose in response to special programs. Such occasions provided an invaluable means of getting to know women who only occasionally frequented Health Partnership. Special events also allowed for a more nuanced assessment of the varying ways in which women received the messages and advice of health care professionals and event sponsors.

Thus on many occasions I accompanied participants into their communities for church services, block parties, city council meetings, HIV educational forums, and fund-

raisers. I was additionally invited to sporadically attend a women's support group that was developed and run by one of the women in this study. Most of the participants in the support group ended up volunteering for this study.

I focused observations on living conditions and the kinds of relationships and social institutions that women defined as an integral part of their survival experience. This research strategy made clear the pragmatic and health concerns associated with particular living conditions among participants. Witnessing women's daily lives also allowed me to assess the tacit details of material conditions associated with housing status and quality, income-generating strategies, and the availability of basic necessities such as food, medication, and electricity.

Being a participant and volunteer at Health Partnership also provided an important means of relationship building with service providers and learning about the provision of care to underserved populations. There were many mornings and afternoons where few women visited the organization while I was there. Inclement weather and/or anticipated disruptions to service programs often meant that Health Partnership would not be busy. Early morning hours also tended to be fairly "slow" in terms of client attendance. During these times, I talked with service providers about their lives, the organization, and their individual service programs.

Health Partnership employees were very generous with their time and protocol materials. Care providers shared their experiences, workshop materials, educational notes, and organization procedures manuals with me. Our conversations frequently centered on the frustrations providers felt in trying to balance clients' needs, organization policy, and federal oversight mandates. This aspect of the research addressed the dynamic context in which women received services, advice, and referrals. I focused more formal inquiries and observations with Health Partnership staff on discerning the particular policies and procedures shaping the range of local services.

To be fair, I must be clear that my knowledge of care providers' social and economic backgrounds and their struggles with the politics and processes of service provision is limited. I consciously chose to focus this dissertation on service recipients. I limited my observations and formal interviews among Health Partnership staff for two reasons. First, the time-intensive nature of ethnographic fieldwork required that I make

difficult choices in terms of with whom I spent my time. I simply could not afford my full attention to both groups of study participants in a sixteen month time period. Second, a nuanced analysis of service provision from the perspective of care providers would have required intensive participant observation in care appointments and in providers' personal life spaces. I worried that spending too much time focused on providers would have socially aligned me with the institution, rendering me as more suspect among women than I already was as an "outsider." In the end, I chose to concentrate more generally on understanding how Health Partnership programs reflected federal funding constraints and local understandings of health needs.

Interviews

As is characteristic of many studies among "difficult to reach" populations, I recruited interview participants through first hand meetings at Health Partnership and through snowball sampling (Bernard 2005). Asking study participants to lend "word of mouth" to this project helped me to establish trust with otherwise skeptical or difficult to reach participants. Snowball sampling also allowed me to better grasp the varying social circles and networks among women enrolled in Health Partnership programs.

My efforts to recruit interview participants were circumscribed by the many research studies taking place within the broader HIV positive community. Gift cards, in particular, provided one mechanism for women's comparison and critique of the various research projects in the area. Most of the operative studies in Midway involved blood donation, substance abuse cessation, and clinical trials. Participants were compensated justly for the intensity and potential risks associated with these projects, sometimes with as much as several hundred dollars upon study completion. Service providers too recognized the efficacy of offering "incentives" for program participation and so offered nominal gift cards for attendance at meetings and events.

This research essentially became enmeshed within the local gift card economy. The study was no exception to the comparisons made between local studies, despite its status as a qualitative study with very different strategies for data collection. Word of mouth soon traveled that all interview respondents received a twenty dollar gift card to a local grocery store in partial compensation for their time. As such, many women sought

me out to hear more about the study and myself. The gift cards, I quickly learned, were low on the priority list because they were for a nominal amount and were not redeemable at Wal-mart. Even so, gift cards became one mechanism for snowball sampling in addition to providing an early lens onto the fabric of women's strategies for survival.

I conducted primary interviews with 40 HIV positive African American women over the age of eighteen. Interviews followed a guide and lasted, on average, an hour and fifteen minutes each. These interviews focused on discerning the socioeconomic contexts of women's lives. Questions centered on rendering visible the ways in which the socioeconomic context of their lives shaped women's priorities of need and health strategies.

Some women found it difficult to sit for long periods of time. In these cases we divided interviews into more manageable segments, sometimes over different days. For the most part, women opted to conduct the first interview in a private room at Health Partnership. Some women preferred the Health Partnership setting because they did not want to talk among family members who would be at home. Other women preferred to meet at Health Partnership because they were not comfortable coming to my home or inviting me to their homes. A few women, however, opted to conduct primary interviews in their apartments. In all cases, women generously shared their personal circumstances of success and challenge in the context of life with HIV disease.

I completed an additional 27 secondary interviews with women from the primary interview group. I began conducting the primary interviews several months into this research. Because I was better established in the community by this time and had been able to form closer working relationships with many of the women in this study, secondary interviews were more collaborative than the primary interviews. By collaborative, I mean that women seemed to feel more open to refining my questions and taking the interviews into directions that they felt were appropriate given their life contexts. This dynamic improved on the original interview guide, particularly given that secondary interviews were concerned with women's perceptions of HIV disease and disease management. Overall, secondary interviews emphasized how the reception of programmatic services shaped women's experiences and perceptions of survival with

HIV disease. Questions focused on how programmatic services shaped women's understandings of disease progression and strategies for navigating the system of care.

A third set of interviews included 11 service providers from the health coalition. These interviews explored the dynamics of care from the perspectives of care providers. In light of the effects of service providers' structural locations on their strategies and philosophies of care provision, these interviews explored how life experiences and federal guidelines that program employees draw from in order to make sense of their roles as providers of care in this setting.

Follow-Up Interviews and Activities

From May to June 2009, I conducted follow-up interviews with ten women from the primary interview group. I selected interview respondents based on insufficiencies in the field record I created through field notes and interview transcripts. I also chose follow-up interview respondents who had potentially life-altering events unfolding at the time I exited the field. Questions focused on recording changes in women's living conditions, health needs, and strategies for achieving stability.

I also conducted participant-observation in women's daily life spaces and at Health Partnership during the follow-up phase of research activities. These opportunities allowed me to assess changes in women's living conditions. I was also able to document changes in support service provision protocol. The new fiscal year had ushered in a few important alterations to service protocol.

This ethnographic account of women's experiences of survival with HIV disease thus relies upon insights from participant-observation and the stories and perceptions of HIV positive African American women and their health care providers. While participant-observation and semi-structured interviews may be considered as "traditional" fieldwork practice, the intent here was explicitly feminist in orientation. I sought to implement this research design in a way that maximized the perspectives of women living with the virus. Such an approach called for a sustained commitment to relationship building and the creation of trust. In the end, women's willingness and courage to shape the direction and scope of data collection played a key role in the data analysis and

interpretation of the various social processes mediating women's strategies for and experiences of health and survival.

Data Analysis

All interviews were transcribed by the researcher. I organized fieldnotes and interview transcripts using NVivo8 software. All research materials were first coded line-by-line to discern general themes in the data. I then organized the data into more specific themes as outlined by the three primary questions addressed by this research: 1). Under what social and economic conditions do HIV positive African American women navigate health and survival?

2). How does the reception of programmatic services shape African American women's experiences and perceptions of survival with HIV disease?

3). Using Health Partnership as a point of reference, what are the dynamics of care programs targeted to African American women, ethnic minorities, and the poor?

Once the data were organized by thematic content, I began the process of discerning social and economic differences among study participants. I began this part of the analysis by creating a chart of study participants that included economic and demographic data, including drug use history and length of time since diagnosis with HIV disease (see appendix 1). I then organized study participants into three groups based on income, percentage of income spent on monthly rental payments, and "disposable income" as figured through the averaged monthly utilities bills of research volunteers. I then "re-coded" interview and fieldnotes content within each group. This final stage of data analysis was focused on discerning shared service utilization and social network trends within each group while spotlighting the differences between groups of women.

CHAPTER THREE:
THEORIZING THE HIV SYSTEM OF CARE UNDER NEOLIBERALISM:
TECHNOLOGIES OF CARE AND SOCIAL NETWORK "SURROGACY"

When I arrived in Midway in August of 2007, Health Partnership was in the midst of a rapid and dramatic reorganization of its services. Prior to my arrival, Midway's branch of the agency consisted of two full-time staff and two or three volunteers from local college programs. Their services had been housed in a single room in the basement of nearby church. Employees could provide only food pantry, pastoral care, and emergency assistance services. Despite their limited programs and funds, Health Partnership served as a crucial resource for Midway's HIV positive population. They were a payer of last resort, meaning that, when all else failed, an HIV positive individual could turn to Health Partnership for financial support. It was in this capacity that the agency was already well- established as a central institution within the local HIV positive community.

The day I first came to Health Partnership marked the arrival of two new employees and the transfer of one existing employee to this particular branch of the organization. No longer could employees and services be housed in a single-room office. Each staff member now had their own office, as well as an employee lunch room and restroom, in a spacious, if old, building. Over the next few months, an additional seven employees were hired to run new, and often officially un-defined, programs. New staff members set about the difficult task of meeting community members, designing their programs, and implementing program protocol in ways compatible with federal oversight mandates. Having been a local presence since 1999[v], the organization and some of its staff had been long acquainted with the health care and support needs of Midway's HIV positive population. However, at this time employees were less well-acquainted with the new protocol and procedures outlined by the Ryan White Treatment Modernization Act (TMA).

The TMA mandated two major changes in how Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds could be used. First, the TMA revised the method for determining the geographic priorities of funding (US Department of Health and Human Services [USDHHS] 2009). The previous formula determined the

funding received by a given area through counting the number of AIDS cases over the previous ten years. As a result metropolitan areas with newer epidemics received less funding than areas where the epidemic had a longer and more visible impact (USDHHS 2005). The new formula, however, counts the living number of cases in an area and considers them with respect to "severity of need." This notion of severity takes into account HIV incidence in addition to levels of poverty and the availability of other support resources (USDHHS 2005). Under the re-definition of geographic priorities, North Carolina was poised to receive $6.5 million more in federal funds than they had in the previous fiscal year. The ways in which new funds could be used, however, was now restricted by the TMA.

The second major change outlined in the TMA mandated that 75 percent of all Ryan White CARE Act funds be used on what is considered as "core medical services." Core medical services included for such needs as outpatient and ambulatory health services, AIDS pharmaceutical assistance, treatment adherence counseling, oral health care, substance abuse services, and mental health care (USDHHS 2009). Conversely, funding for "support services" such as case management, transportation, pastoral care, and emergency financial assistance had to be limited to 25 percent of the funding total. To ensure that states adhered to the "75/25 funding split," individual organizations would now be required to provide explicit and detailed documentation of how they spent and distributed federal grant money. Health Partnership's Executive Director explained that,

> The other thing that's happened…is that Ryan White is much more
> medicalized than it was when it started. It's about medical service.
> It's about medical outcome. It's not about paying rent. It's not about
> making sure utilities stay on. And originally it was. It's a very
> significant shift in how we can serve our clients (Mary).

Mary explained that the TMA presented a fundamental shift in how Health Partnership could meet their clients' needs. While Health Partnership was preparing for an influx of available funds, they were also preparing to restrict access to particular types of assistance in accordance with federal guidelines. It was clear that in this new policy context, the TMA regimented care providers' work activities and expectations in particular ways. Although the staff-related difficulties engendered by the new legislation are not the focus of this research, it should be noted that employees consistently worried

about and sought solutions for how to balance local conditions of need with restrictive federal guidelines.

It was in the context of changing legislation, rapid growth, and agency transformation that I learned about the services used by women living with HIV disease. Although Health Partnership had been a pillar of the local community for many years, its presence in Midway was not the same as it was in years past. New programs, new service guidelines, and new eligibility rules defined the institutional landscape through which individual service providers sought to care for and assist clients in need. This climate of change shaped, in part, how Health Partnership employees understood and discussed their roles as providers of care and service administrators.

Program Employees

Health Partnership employees included six African American women, two African American men, two White women, and one White man. All employees reported coming from "middle class" backgrounds, although a few employees discussed the precarious economic nature of their "middle class" status due to single-parenthood and/or financial debt. Some employees had long ago struggled with substance abuse and/or intimate partner violence. All employees discussed having close family members or friends who lived in poverty. As such, most employees regarded the challenging life circumstances faced by their clients as familiar terrains.

Employee educational backgrounds ranged from having graduate degrees and certifications to completion of a high school diploma. Only one employee reported no education beyond high school. Thus most employees had specialized certifications and degrees in addition to their experience and training as AIDS service providers. The apparent preference for employees to have specialized credentials were, in most cases, state mandated. State-level job descriptions defined necessary credentials as health-oriented or social work education and/or years of experience working in an HIV positive community. The general trend, it seemed, was that local AIDS services were being increasingly professionalized. In this context, employee educational backgrounds included social work, health education, counseling, divinity, and nutritional science. In

all cases, employees felt that their educational backgrounds shaped, to varying extents, their strategies for the provision of AIDS care.

In addition, Health Partnership employees had personal motivations for working at an AIDS service organization. Natasha, for example, switched from working at a "traditional social work site" to an AIDS service organization after learning that a former classmate in her hometown was diagnosed as HIV positive. For Natasha, the realization that "AIDS was that close to me" prompted her to think about the epidemic in community terms. She often discussed HIV disease as a social problem that should be addressed by the Black community. Focusing her social work skills on issues of HIV/AIDS became one means for her to address a community need. Most employees similarly felt that, given their own backgrounds and personal histories, AIDS care work was an extension of their commitments to community, family, and, in some cases, faith. Thus the programs and procedures of the AIDS care continuum were implemented by social actors who had varying economic, personal, and professional motivations shaping their engagement with federal AIDS care policy and procedures.

The Programs and Procedures of the AIDS Care Continuum

Midway's HIV/AIDS public health care system provided an important part of the context of women's health experiences and strategies. "The system" was officially described by social program representatives and policy makers as a care continuum consisting of providers who followed federal mandates and agency-specific guidelines. These guidelines offered an administrative blueprint for the provision of health care, health advice, and economic resources to Midway's HIV positive population. While any HIV positive individual may access the continuum of health care and support services, the federal government targets this comprehensive health service strategy to women, ethnic minorities, and poor populations who are otherwise underserved by the health care system (USDHHS 2006). In this conceptualization, "the system" is an amalgamation of policies and programmatic services that are designed to address obstacles to health care and treatment adherence. Obstacles can include such circumstances as lack of health insurance, homelessness, substance abuse issues, and financial hardship.

Unofficially, Health Partnership functioned as a source of emotional and social support for HIV positive individuals who needed advice, encouragement, and compassion. Service providers were often available for informal conversations with clients struggling to maintain stability. Clients who needed "extra" support were invited to join employees on cigarette breaks. On many occasions, I witnessed employees and program participants laughing and talking together. These occasions seemed to generally "lift the spirits" of people facing difficult and emotionally draining health challenges.

In Midway, hospitals, clinics, and a few community-based organizations receive federal funds for the treatment and care of people living with HIV disease. Health Partnership is the only one of these organizations that houses several Ryan White-funded programs under a single roof in a community-based setting. Health Partnership is Midway's largest HIV support service provider and, as such, is a central institution in the broader system of care and programmatic services. Its role as a point of access to and retention in medical care means that agency representatives maintain close working relationships with physicians, medical clinics, hospitals, pharmacies, and the North Carolina HIV/AIDS care consortium[vi].

Health Partnership consists of three separate office buildings and two residence facilities across three cities. Two of the office buildings are used for the provision of client services and programs, while one building houses administrative employees. The office through which I conducted this research focused on the provision of client services to roughly 200 individuals living in two counties, although the vast majority of clients served in this location were from the county in which Midway is located. Here I refer to this particular office as "Health Partnership," although technically the name encompasses a larger entity of personnel and clients.

Health Partnership is located in one of Midway's most economically distressed neighborhoods. At the time of this research, dilapidated houses lined the streets along with empty buildings, abandoned homes, and the remnants of demolition jobs left long unfinished. On any given day, people could be seen walking to and from the corner store where it was advertised that food stamps and WIC vouchers are accepted in payment for the vast array of discounted meats. On pleasant days, bus stops in the neighborhood bustled with activity as children and adults alike congregated to catch their rides to other

parts of town where there were full service grocery stores, shopping centers, and movie theaters. As a shopping destination, this particular neighborhood could offer little other than industrial supplies, high-priced convenience stores, and a few small locally-owned restaurants boasting "soul food," "country cooking," or "a taste of home." Home-based day care centers, churches, and community-based program offices dotted the neighborhood landscape.

Just beyond this neighborhood lay a recently "revitalized" greater downtown area. The "new downtown" concept was based around growth projections among Midway's financial sector, real estate markets, and neighborhood-based corporate retail ventures. Amid relatively quiet lawyers' offices, commercial banks, and consulting firms sat bustling social service buildings, a high rise housing project, a drop-in center for homeless populations, and several drug treatment facilities. The colorful and well-kept building facades of the high finance private sector provided a stark contrast to the relatively muted exteriors of buildings that housed public programs for low-income populations.

Health Partnership sat approximately two miles from the portion of Main Street associated with the "heart" of downtown. There were no large signs to indicate what the organization was about or for whom it was intended. As a general rule of privacy, Health Partnership did not disclose its purpose to passersby or to those who walked in to find out about the organization. This rule was immediately reinforced by a prohibitive exterior designed to conceal the inner goings on.

Health Partnership's parking lot was surrounded on all sides by a chain-link fence topped with barbed wire. The fence was closed on all sides after business hours to protect the property and building from break-ins and vandalism. Around the front of the building, the doors were made of bullet resistant glass. Upon entering the glass doors one stood in a small foyer with a locked wooden door between themselves and Health Partnership's lobby. Another sheet of bullet resistant glass divided visitors and the front desk area. Front desk personnel "buzzed" in any visitors they recognized as clients or other agency staff. Anyone seeming "out of place" or "nosy" was helped through the glass until further assessment could be made.

On first experience, Health Partnership seemed foreboding. It quickly became clear, however, that the security measures were appreciated by staff and clients alike. In addition to protecting the privacy of clients, building security was a safety precaution. On more than one occasion, physical fights migrated from surrounding homes, into the streets, and onto the sidewalk in front of the organization. Gun fire in a neighboring home prompted a police stand-off and Health Partnership's mandatory "lock-down" for a few hours one afternoon. And, there were a few occasions where Health Partnership employees received threatening phone calls, voice mails, and e-mails from disgruntled and emotionally distraught clients. Bullet holes in the agency's windows hinted at the complicated dynamics among Health Partnership, neighborhood residents, and Midway's HIV positive population. At the core of these dynamics were the programmatic services through which Health Partnership distributed financial support and other health-related resources to their clients.

Under the Ryan White CARE Act, Health Partnership received funds for a variety of programs that are integral to building a system of care that could meet the intensive service needs of impoverished and historically disenfranchised populations. For several years prior to this research, the organization housed programs for emergency assistance, nutritional assistance, pastoral care, and the AIDS Drug Assistance Program. HIV positive women had long been able to request rental and utilities assistance along with medication assistance and weekly packets of food. Some women and employees alike would recall "the good days" when it was "easy" to get and give what was needed. For example, my first day as a participant-observer at the organization coincided with a massive delivery of Ensure nutritional drinks for clients. I helped employees and clients unload more than 500 cases into Health Partnership's hallway. Clients were abuzz with excitement because, due to federal Ryan White contract delays, they had been unable to receive their Ensure for several months. In the past, any client with a valid prescription could receive two cases per month. Physicians would often write prescriptions to be valid for an entire year so that a client could pick up their monthly allotment of Ensure with minimal hassle. This month, however, was different. The Treatment Modernization Act had been recently enacted by Congress and was beginning to be implemented at the local level. New federal guidelines mandated that each client get a new Ensure

prescription every four months. Most clients had to visit their doctors before they could receive their liquid nutritional assistance. This small change foreshadowed the systematic implementation of federal policies and programs aimed at implementing HIV/AIDS care programs in ways that emphasized oversight, medication and treatment adherence, and disease outcomes.

Under the Treatment Modernization Act, Midway's HIV/AIDS system of care continued to include emergency assistance funds. Emergency assistance funds are provided through the Housing Opportunities for People With AIDS program (HOPWA) and through Ryan White legislation. Both streams of funding are federal in nature and are specifically designated as payers of last resort. Together these funds accounted for about $14,000 of federal money distributed every month through Health Partnership. Ryan White funds in particular provided $10,000 of each month's available money. Emergency assistance funds were officially available for helping an HIV positive person in need pay their monthly rent and utilities.

As a provider of last resort, the "emergency" component of the funds was supposed to be strictly enforced. Yet, as one service provider explained, if Ryan White budgets are not spent in their entirety, that money is forever lost to the state of North Carolina. Greg explained that:

> When I first started, I just kind of had the mentality like is it in my budget? I know if I don't spend this money out, we won't get it back for the next fiscal year. So I would just spend and I would help anybody regardless of the situation if they were showing up here with a need.

Greg's former strategy of allocating his money solely on the basis of request soon changed with the advent of the Treatment Modernization Act. In his estimation, program procedure had to be "tightened" to compensate for new oversight guidelines and the decreased amount of available money for "support services." The realities of how the budget worked, however, did not change. Greg still had to spend each month's money in its entirety or lose that money for the next fiscal year. To reconcile these realities, a person applying for assistance was required to prove and *justify* their need.

First, clients requesting emergency assistance were often required to bring in an eviction notice from their landlord or a letter of disconnection from the utilities company.

Officially, it was never entirely clear to the emergency assistance counselor whether such documents and dire circumstances were mandated. This policy seemed to be more informally implemented and strategically used during times when the organization was waiting to be reimbursed by the federal government for their services. In other words, requiring documentation provided one means of prioritizing the distribution of funds when resources were scarce.

In addition, Greg strategically prioritized rental assistance applications. Aside from wanting to avoid seeing a client evicted, Greg knew where he could "buy time" for clients. For example, local utilities companies granted disconnection notices 21 days past the due date before their services would be cut. A regular monthly bill maintains its original due date. A disconnection notice could thus allow the emergency assistance counselor to make verbal commitment for payment on behalf of the client without having to actually pay for another three weeks. Such a strategy kept clients' power on and kept Health Partnership from overextending its budget in any single month. The drawback, however, was that clients would often wait until their circumstances were dire before coming to the organization to discuss their support options. In some cases clients lost power or were evicted because they had been unable to schedule a timely appointment for assistance. In other cases clients were denied support because the organization was on a spending freeze. Thus this strategy of positioning one's self as undeniably in need of care from the provider of last resort could be risky.

The second emergency assistance protocol criteria was that clients were required to explain how they had spent their money that month and why in that particular month, or months, their income was not enough to meet their needs. For some women, this task was fairly simple. They would attend their appointments with receipts for hospital bills, car repairs, and/or insurance premiums in hand. Non-payment of rent or utilities bills could be justified with acceptable unexpected or unavoidable expenses. For example, Taylor found herself unable to pay her rent and utilities one month. Over the course of a few short weeks, she was required to purchase several books for her undergraduate coursework and needed to buy a bus ticket to visit her seriously ill daughter. Before purchasing the ticket, she spoke with the emergency assistance counselor to make sure that she was not mistaken in her strategy. It was only after being assured that she could

get assistance that she went ahead and made the purchase. Kareese, on the other hand, experienced the emergency protocol differently. Kareese scheduled an appointment for emergency assistance when she realized that she had mis-spent her rent money for the upcoming month. After a particularly stressful day of fighting with her husband, Kareese had relapsed and spent her rent money on drugs, alcohol, and expensive new tennis shoes. She returned the tennis shoes the following day, but could not undo the fact that she had spent half of her rent money on drugs. Before her scheduled appointment, Kareese confided in me that she was not planning on disclosing where her money had been spent. Just minutes before her meeting with the emergency assistance counselor, she was trying to think of how she might explain her situation without disclosing that she had relapsed in her recovery. She feared that the organization would not help her because of how she had spent her disability check. In the end, Health Partnership did provide Kareese with the financial support she needed, but she felt she was lectured and shamed by staff for spending her income in a technically inappropriate way. Kareese was, however, grateful for the assistance she received and acknowledged that the financial crisis was "her bad."

Finally, clients who requested emergency assistance funds had to have proof that they have attended health care appointments as prescribed by their physician. Proof in this scenario most often consisted of up-to-date laboratory print-ups indicating the amount of HIV virus in their bloodstream and the number of CD4 cells in their bloodstream[vii]. Theoretically, reviewing this laboratory work over time provides one means of assessing a client's compliance with physician recommendations and adherence to medication regimens. To my knowledge, there were extremely few clients who were turned away because they had failed to attend medical appointments as prescribed by their physicians. Clients seemed to generally understand and follow this rule with no resistance. For clients who did not display favorable health outcomes on their laboratory work, they were provided with medication adherence counseling rather than being denied services.

Taken together, all of these formal and informal requirements most often meant that a client would come in needing two or three months of rent and/or several months of utilities payments. Whether a client received the full amount requested depended on the

funds available, their history of using emergency assistance, and their ability to sway Greg to use his discretion in their favor[viii]. Kareese, for example, explained that Greg had given her the assistance she needed because she had been working hard to maintain sobriety and "live right," despite that she sometimes "messed up." Indeed many women in this study who struggled with chemical dependency or other such technically "unacceptable" financial burdens could count on their powers of persuasion to help them out of a financial jam.

Greg was one of the few "original" members of Health Partnership. His status as "an original" was important to clients who were distrustful of the restrictive changes ushered in by the TMA and the agency growth that was rapidly taking place. Greg's status also meant that he had known many clients for a number of years. He was familiar with the trajectories of most clients' housing situations and economic circumstances. More than half of the daily phone calls coming through to the organization were for Greg. Easily three quarters of the "walk-in" clients who would come to the organization were for him. When it came to receiving timely and personalized service he was, in the words of one woman, "the Man."

In addition to emergency assistance funds, Health Partnership provided funds designated under the categorical umbrella of "medical case management." Medical case management was a new "core" service provision category implemented as a result of the Treatment Modernization Act. Much like emergency assistance, medical case management was designated as a payer of last resort. Clients could request funds to assist with HIV medication co-payments and/or co-payments for non-HIV related medications that were approved by Medicaid. Clients could also request support for dental work and co-payments for physician appointments. Thus as the medical case manager, Monica served as the distributor of medical case management funds.

Monica's job description also required her to serve as an administrator for enrolling clients into the state's AIDS Drug Assistance Program (ADAP). ADAP is an HIV medication program that is jointly funded by individual states and the federal government. In North Carolina, un-insured HIV positive individuals who have an income at or below 300 percent of the poverty level qualify for participation in the program. ADAP provides free medications for the treatment of HIV disease in addition

to medications for the treatment of opportunistic infections associated with HIV disease. The ADAP medication list includes anti-retroviral, anti-depressant, anti-lipidemic, anti-hypertensive, anti-diabetic, and anti-microbial medications, to name just a few of the available drug classes. The drugs and drug classes included on the ADAP medication list treat ailments and infections that are considered as common to individuals with HIV infection such as metabolic disorders of the liver, diabetes, hypertension, and depression. Monica's job in this particular program was to help eligible individuals complete the application paperwork for program enrollment. Enrollment provided clients with free medications.

Monica's other programmatic responsibility was to function for both drug assistance programs as the treatment adherence counselor. Indeed, part of Monica's criteria for the dispersal of Ryan White medication funds was that clients indicate their commitment to and understanding of their medication regimens. This informal requirement of the medical case management program emerged over time in response to Monica's increasingly restrictive monthly budget. For example, in a typical month Monica could distribute $4000 of Ryan White money for medication co-payments. At roughly three dollars per co-payment, this could potentially cover a lot of medications. However, the need for medication assistance consistently outweighed the available resources. Many clients found themselves with co-payments for as many as fifteen medications per month. At roughly $45 per month per individual, Monica could help only around 89 applicants out of the roughly 300 clients that the organization serves. Likewise, funds available for dental work and doctor's visits were scarce resources that were far exceeded by need. Monica could distribute only around $800 of Ryan White money per month for these needs. At roughly $10 per physician visit and $250 for the average dental visit, this portion of the money was often promised months in advance of the payment.

Despite her budgetary constraints, Monica was considered by many women in this study as a close ally to clients. Her entry point into the community, however, was as a general case manager at another social service organization that serves HIV positive populations. Her ties to the community were more personal in nature because she lived in Midway among many of the clients whom she served. Her "insider status" provided

her with a vantage point for understanding the stresses and strains experienced by clients on a daily basis. This understanding, in turn, gave Monica what she referred to as "a way to come at clients from a place of empathy." Empathy can be an important service provision tool for building and communicating trust with persons in distress.

Leslie, for example, created and implemented Health Partnership's newly funded outpatient substance abuse program. The program itself was defined in TMA legislation as a core medical service. Protocol for the design and implementation of substance abuse programs, however, was not outlined in the legislation. Per Health Partnership's organizational philosophy, individuals could not be denied services based on drug use habits, drug use history, or unwillingness to attend drug cessation programs. While clients are not officially required to attend substance abuse counseling or support groups as a condition of using Health Partnership services, they may be referred or prompted by organization employees on several occasions. For example, Lady E. began her road to recovery just as I began this research. For two months before I arrived, she attended bi-weekly substance abuse meetings at a local university hospital. Despite her apparent personal commitment to maintaining sobriety and her institutional commitment to the hospital addiction recovery program, Leslie consistently asked Lady E. to attend Health Partnership's substance abuse recovery meetings. Leslie felt that Lady E. would be a good "role model" for others in the program. She also felt that Lady E. would have a better chance of maintaining sobriety if she were connected to more than one support group. On a few occasions, however, Leslie also commented that she needed to "fill her group out" to ensure that this part of her program remained in operation. Lady E. was never penalized for her decision not to attend, but was prompted on several occasions to join the group.

Armed with the official organizational philosophy of empathy and non-judgment in mind, Leslie created Health Partnership's substance abuse program to loosely mirror the traditions of the "motivation enhancement technique" (MET). MET is a systemic approach to drug addiction therapy. Based on the principles of motivational psychology, the primary goal is to produce rapid, internally-motivated change. Engendering "internally-motivated change" meant that Leslie endeavored to help illicit drug-using clients decide for themselves that it was time to quit. Leslie applied such conversational

strategies as assessing a client's personal risk of illness, death, social ostracism, and financial hardship due to drug use. She further emphasized one's own responsibility for change. These strategies were accompanied by notions of empathy, advice to stop drug use, and the creation of options to produce change. I joined Leslie and Chantelle one day during an informal conversation about the difficulties of being homeless and chronically ill. Leslie listened intently as Chantelle described to her the frustrations and obstacles she faced for achieving daily life stability. Leslie acknowledged Chantelle's feeling that she had "got the run around" from service providers who were supposed to help her obtain much needed identification cards. Leslie further nodded in agreement when the woman discussed the anger and sadness she felt at being treated unfairly by people who were supposed to help her. At the end of the conversation, Leslie responded with, "Wow, that sounds really hard. But let me ask you this: Do you think things would be easier for you if you quit using? I mean would you be treated different if you didn't use?" Thus began a conversation between Leslie and Chantelle about strategies for changing the role of addiction in her life. Leslie then continued using these techniques with Chantelle in a group format in addition to one-on-one counseling sessions.

As a woman who has traveled the roads of recovery, Leslie worked hard to facilitate shared dialogue with her clients. Her most important tool, she described, is self-disclosure:

> And if I'm with women, I'll talk about my sexual past, my personal history, and being in active addiction. Because staying drunk all the time, you get screwed a lot when you don't plan to. People are more comfortable talking to somebody who you think has been there.

Self disclosure, as Leslie so aptly stated, is a strategy for increasing communication and trust between herself and her clients. Although at the time of this research Leslie was a "new-comer" to Midway's HIV positive community, her personalized strategies for relationship building provided a means for bridging the gap, so to speak, between herself the professional care provider and clients in need of her professional services. Thus much like Greg and Monica's programmatic procedures for financial assistance, protocol for outpatient substance abuse counseling services were also drawn from knowledge and trust based in personal circumstances and relationships.

Much like its substance abuse program, Health Partnership's risk reduction counseling program was strictly voluntary. The federal program protocol is known as Comprehensive Risk Counseling Services (CRCS). CRCS is an individually-oriented risk reduction and intervention service. Risk reduction strategies in this context applied primarily to reducing one's risk of HIV re-infection or transmission. However, the program itself is based in the philosophy of one's right to self-determination. Clients chose which risks they wished to reduce in their lives so long as they could be related to efforts aimed at minimizing one's chances of HIV infection and transmission. Social obligations, legal matters, financial obstacles and strategies, drug use behaviors, and sexual behaviors could all fall under the purview of CRCS. One woman utilized the CRCS program as a stepping stone for starting her own business. She and the CRCS counselor would spend their sessions together writing business plans, figuring out budgets and revenues, and ordering cost-efficient materials for the business. As they completed these business steps, they would discuss the ways in which financial security and autonomy could reduce the client's need for and risk of engaging in condom-less sex.

Because CRCS requires the disclosure of potentially damaging and otherwise sensitive information, trust was paramount between the CRCS counselor and her clients. In North Carolina, failure to use a condom and/or failure to notify one's partner of their HIV positive status is in violation of public health laws. The violation is punishable by fines that can reach three hundred dollars or more and, as seen periodically on the news, incarceration. CRCS is one program where reporting requirements do not include notification to police or other social service agencies. Clients are free to speak about practices and behaviors that are considered as illegal or potentially endangering of others. Paula, the CRCS counselor, achieved trust in this context by maintaining a service provision philosophy based in strategies for building trust, maintaining distance, and communicating empathy. Paula's professional demeanor paradoxically relied upon connoting caring and compassion while making clear that she does not care enough about a person's personal habits to "tell their business." As Paula described,

> "I don't really care too much who it is, but what are you doing and
> getting into the frame where I know this is personal. And I don't
> care. Like I care to a certain extent, but I don't. Not enough to put
> your business out there, you know. But it's about being real and

being there for them to give them whatever that they need to fill that
void.

Paula's service provision style, while certainly different from the strategies of self-disclosure utilized by Leslie, lent a particular type of formality to her program. This formality, in turn, created a programmatic structure that felt conceptually distinct from the more informal dynamics favored by the emergency assistance service and the substance abuse program counselors. Paula's strategy of "professional distance" was appreciated by clients who needed someone to which they might safely disclose sensitive information. Thus while all of Health Partnership's programs and procedures may be housed under one roof and one guiding philosophy, there is considerable variation in "the feel" and strategies of different programs.

Of all the federally funded AIDS care programs at Health Partnership, non-medical case management was known among women as the most rigid and systematically implemented. Under Ryan White legislation, non-medical case management provides assistance for a variety of needs that are not directly health-related. While a case manager may provide clients with advice and assistance in choosing a doctor, they do not follow up on medical appointments, diagnoses, and treatment regimens prescribed by physicians. Most often, non-medical case managers focus on helping clients who have needs that are social, legal, and/or financial in nature.

As a support service, non-medical case management accessed funds that were part of the "25 percent split" in order to pay case manager salaries and keep their programs running. "Support service" status meant that case managers had to be perhaps more mindful of federal budgetary constraints and oversight mandates. While case managers did have the discretion to distribute emergency assistance funds, clients tended to see program guidelines as more rigid and less likely to pay out without "hassle." In many cases, women opted to wait several days for an appointment with Greg rather than scheduling an appointment with either Bert or Natasha, the agency's case managers. This meant that Greg was frequently over-booked. If the client had waited for "emergency status," they usually had to schedule the appointment with another case manager.

When asked to describe the "hassle" of using case management, however, many women referred to the service provision style used by case managers rather than

institutional rules. In the agency context, Ryan White funded case management was largely a referral service aimed at increasing access to health care and related programs. As social workers and health educators, case managers provided the primary points of contact between clients and other programs within the system of care, including medical services. Case managers worked to facilitate enrollment in social programs, greater understanding of HIV disease, and the "empowerment" of individuals to take responsibility for their health and their daily life circumstances. Empowerment was theoretically achieved when a client could maintain their health care regimen and finances with little or no support from programmatic service representatives. However, according to Natasha, empowerment of a client had not yet happened in her career. Still, with the empowerment to produce one's own good health outcome as an ultimate programmatic goal, case management was in this context implemented as a short-term program. As Natasha described it,

> "…case management is only there to help you from where you are diagnosed. If you are newly diagnosed then you maybe need to get medical services, nutrition, housing, --we help you get all that established by connecting you with Medicaid. Applying for social security—as far as appeals and denials—looking at housing, finding food. But after a certain amount of time, with all that established, then what is there a need for us to do?

Natasha describes how the goals of case management are achieved through service enrollment. Bert, however, explains the other component case management:

> All of the things about finances, household, and medical care are very important. But you can look at it like, how does the person keep their appointments? How responsible are they when it comes down to appointments? If that's their concerns or are they just concerned about getting their rent paid now. The most important thing is your health and if you're not in compliance with that, it's really not no need for me to help you. You will be sick anyway.

Bert's explanation of the guidelines for assessing a client's progress within the case management program underscores the strategic need for clients to communicate an earnest desire to achieve "health empowerment" in order to receive support. This meant that, much like contemporary welfare programs, utilization of the AIDS care services described above is theoretically supposed to be a temporary measure. Over time, clients should be "hooked into the system" securely enough to navigate their own way through

medical care and survival with HIV disease. Clients reported feeling as though they were not trusted by case managers because they asked a lot of questions about current circumstances and potential strategies for avoiding such circumstances in the future.

In addition to housing emergency-based and "temporary" programs, Health Partnership housed long-term programs that were funded through means other than the Ryan White CARE Act. These programs included a weekly food pantry, a nutritional assessment service, and a pastoral care program. These programs were not Ryan White funded at the time of this research, although agency administrators think it likely that nutritional assessments will be federally funded in the future. The food pantry operated through funds provided by individual donations, agency fund-raisers, the State Nutritional Assistance Program and the Federal Emergency Management Agency[ix]. Each client who was in compliance with the state HIV/AIDS consortium's yearly update policy was able to "shop" the food pantry once weekly for approximately 15-25 items. Each client received one protein item such as frozen hamburger meat or frozen chicken in addition to whatever fresh produce and canned goods had been donated or were available at the food bank distribution center that week. Although the pantry inventory varied greatly from week to week, clients could generally count on several nutritious, if sometimes less than mouth-watering, choices.

The pastoral care program is one of the founding programs of the agency. In years past, pastoral care has been considered as "psychosocial support" and thus as part of Ryan White Care Act programs. The implementation of the TMA ushered in new definitions of psychosocial support which did not include pastoral care. The agency now pays for this program through their fund-raising efforts. It is, in other words, an agency-sponsored service. Any client who wishes to speak with the pastoral care counselor can do so at any time. Doug, Midway's pastoral care counselor, was an eager listener who worked hard to maintain good working relationships with clients. He accepted walk-in appointments and pre-scheduled appointments alike. He made house calls when necessary and prided himself on being a patient and active listener. In addition to serving as a faith-based, non-emergency counselor, Doug matched clients with local "care teams." Care teams usually consisted of several members from an area church congregation who wanted to provide spiritual support and companionship for a person

living with HIV/AIDS. While this particular program did not receive federal funding and did not have the relatively large budgets of other services, it nonetheless served as an important component in many women's experiences with the system of HIV/AIDS care.

Lisa, for example, spoke informally with Doug on a regular basis. At the time of this research she did not have a care team. Lisa had participated in the program in the past and had recently attended an agency-affiliated spiritual retreat for HIV positive individuals. One afternoon Lisa and I were talking privately in a conference room at Health Partnership. She had been recently bothered by a series of dreams that she characterized as being suicidal.   In her dreams, Lisa jumped off of a mountain side, but always awoke before she hit the ground. Lisa discussed how she awoke from the dreams feeling anxious and confused, but not exactly afraid. Lisa also often discussed how lucky she felt to be alive. Yet, she wondered why she kept having the dreams, even though she did not feel as though she wanted to hurt herself. The dreams were occupying her thoughts and made her uncomfortable. She decided that she would talk to Doug about the dreams to see if he had any insights as to how serious they might be. Doug had known Lisa for several years and was confident that she was not suicidal. He talked with Lisa about the spiritual symbolism of cliff jumping. He suggested that Lisa's recent attendance at the spiritual retreat was a "jumping off point" for a new spiritual journey. He advised her to view the jump in metaphorical rather than suicidal terms. This advice calmed Lisa's fears that she might be unknowingly suicidal and provided her with an alternative means for understanding an otherwise unsettling series of dreams and thoughts. Thus although Lisa might not consistently participate in Health Partnership's pastoral care services, they represented an important health resource to which she could turn in times of need.

The eight services described above are designed to operate together as a "safety net" for individuals who are in danger of dropping out of medical care or experiencing interruptions in medication adherence. While Ryan White-funded programs represent one of the largest public health efforts in American history, they do not operate in isolation. Rather, the system of HIV/AIDS support services and medical care articulates with other federal social programs. The institutional context of HIV positive women's

lives can include several other programs and policies that dramatically affect their abilities to care for themselves and their HIV health.

Social Programs Use Beyond the Ryan White CARE Act

In addition to HIV/AIDS support services and more commonly known welfare services such as The Women, Infants, and Children Program (WIC) and Temporary Assistance to Needy Families (TANF), the women in this study drew support from myriad other social programs. The Social Security Disability Insurance (SSDI) and Social Security Insurance (SSI) programs[x] provided the backbone of many HIV positive women's survival strategies. Monthly disability insurance payments were an important means of income generation and access to other related support services such as subsidized bus passes and other forms of transportation assistance. Women who qualified for disability insurance payments based on their HIV positive status met two health criteria: first, they had been diagnosed with AIDS. Second, they had experienced at least two opportunistic infections since diagnosis with HIV/AIDS. Being granted disability status was a goal for many women who felt physically and/or emotionally sick due to their HIV positive status. It was also a goal for women who reported no illness symptoms, but who had few other options for steady income generation.

Monthly disability payments could range from $623 to more than $1000, based on one's work history and the amount of money they have paid in Social Security taxes. From a service provider standpoint, making ends meet on a disability income is a difficult road, so to speak, that should be avoided. Greg explained why he counsels clients to avoid enrolling in disability benefits programs when they are still young enough to recover their health and find employment:

> This is what you guys have agreed to live on for the rest of your lives.
> I don't know why they would wait around for two or three years to collect
> Disability when they don't know they don't have that much of a work history.
> Their disability check is going to be 500 a month and it'll be like that
> for rest of their lives because you haven't put into the system (Greg).

Greg explained that monthly disability incomes can be meager. His point that disability status would not solve women's economic problems is well-taken. Yet, women's

decisions to apply for and receive disability payments reflected much more than the "waiting to collect" mentality that Greg described during our interview. Enrollment in the disability income program reflected a variety of factors and daily life conditions other than health. The reality among women was that employment was no simple task. Disease symptoms, depression, history of incarceration, mental health issues, and drug addiction shaped women's abilities to compete in the local job market. The reality for many women is that they were unable to find full-time, well-paying employment.

Along with the resources provided by other social programs, disability income was seen as a luxury by women who did not qualify for the program and who endeavored to find stable, well-paying employment. Marjorie, for example, struggled to feed herself and her two young sons on income generated from part-time, insecure work. Marjorie attended a free culinary school program in the afternoons and then sought work as a day laborer after her courses each day. She most often found work in construction and construction site maintenance. This work was sporadic at best and was physically taxing. Although Marjorie was in good physical health, she found it physically and emotionally draining to attend classes in the morning, perform manual labor in the afternoons, and then care for her children in the evenings.

On several occasions, Marjorie came into Health Partnership sweating, rushed, and out of breath. She hurried to the organization on her lunch break at work so as not to miss being able to shop at the food pantry. More times than not she came in "hot" because she felt that she was physically working harder than the men around her. She could not quit this work, however, because it was all she could find that would grant her the flexibility she needed to care for her children (one of whom suffered from a chronic kidney disease) and attend school.

Throughout the course of this study, Marjorie struggled to make ends meet on a monthly basis, sometimes earning as little as two hundred dollars a month. The difficulties of paying monthly bills through part-time, insecure work were exacerbated by Marjorie's disqualification from welfare cash assistance services. After the birth of her first child, Marjorie's boyfriend was released from prison. He had plans to move in with Marjorie in order to help her with the baby. Their plans were supposed to be kept secret so as not to alert welfare officials that an aid recipient was living with a convicted felon.

Upon his release, he was required to provide address verification. Unfortunately for Marjorie, he gave the Department of Corrections her address without realizing the consequences this mistake would have. As she explained,

> Just by him putting my address on there—I don't know what social services had to do with this, but I think it might have been for his probation officer and all that tied in. And my address kicked back. And when my address kicked back, it went to Social Services. Well I got put out. They put me out of my house. I had a house. I had a home. They put me out. They sent me a letter. I went to go walk to the mailbox to get my check and my check was not there. It was a letter saying that my check was cut off. I had 30 days to move.

With no monthly welfare check for the care and support of her child, no housing, and diminishing support from her boyfriend, Marjorie entered the HIV/AIDS system of care. However, she soon found that income generation would remain a problem in her daily life. Marjorie learned that she did not qualify for disability income because she had never been diagnosed with AIDS. In her estimation, people who are eligible to receive income assistance are "more lucky than they can imagine." Perhaps not surprisingly, her lack of financial support translated into resentment of "…a system that don't make sense:"

> I'm like is there anywhere else I can go to apply for some help? And they like, 'no because this right here.' We keep coming back to this. Hey, that guy has been in federal prison for six years. But you know something—he's living better than I am living. In federal prison, he has cable. I don't have cable. He has radios. He has everything. He's just not free. In a way I'm not free. Because it's like I'm running into walls. Everywhere I turn, you keep those walls no matter what I do to be better. It's frustrating (Marjorie).

Marjorie's views of "the system" were largely based on her experiences with applying for and being denied monthly benefits. While cash benefits such as SSI, SSDI, and TANF can seem like luxuries for women who do not qualify for them, the realities of living off of a public assistance income are not quite so appealing. For example, Ashley received $649 per month in SSI payments. She paid $300 per month for rent and approximately $150 per month for utilities. After purchasing groceries, paying for her cellular phone, and paying her monthly life insurance and car insurance premiums, Ashley's budget was at a deficit. Recognizing her relatively good health, Ashley, like many women in this study, searched for employment to supplement her monthly SSI payments[xi].

Women who receive less disability money than they need for survival may utilize Vocational Rehabilitation services (VR) as a resource for finding part-time employment that does not affect their disability status. VR services offer job training and skills training for disabled populations. VR services typically include programs for building skill sets such as those needed for medical transcription, legal clerical work, accounting, fiscal management, and public safety licensing. VR services also provide tuition assistance for individuals who seek to complete education for any of the particular career tracks supported by the VR program. Jayla used VR services to complete a certificate in medical transcription. As we talked through our first interview together, she pointed out her framed graduation certificate for the program. At the time she completed the course, Jayla was working as a cook in a restaurant. A series of falls combined with her discomfort around being HIV positive and working in a kitchen led Jayla to pursue a career change. She talked of how proud she felt at being a "top student" in the class. Her VR counselor had supplied Jayla with letters of recommendation and other forms of moral support for finding employment in her new field. Unfortunately, Jayla's career change was not to be realized. Two months after she completed the course, Jayla had an accident and underwent several painful back surgeries that left her unable to work. Jayla still viewed graduation as "one of the proudest and happiest days of [my] life."

Like Jayla, many women in this study tended to use VR services for the creation of employment options that are less physically-taxing and more flexible than construction and housekeeping for local businesses and hotels. In particular, VR services' Certified Nursing Assistant (CNA) licensing program was popular among the women in this study. The CNA licensing program was relatively quick, readily available, and lasted only three months on average. In addition, CNA work was seen as "flexible" by women who sometimes battled fatigue and depression. Should a woman find private work as a home health aide, she could negotiate her weekly schedule with the person for whom she cares. For example, having worked with her client for more than five years, Ashley negotiated with her client for a three month hiatus from her care-giving duties. Ashley frequently battled bouts of depression that coincided with painful outbreaks of genital herpes. At the onset of an outbreak that resulted in debilitating feelings of unhappiness and anxiety, Ashley felt it best to rely solely on her disability income. During this time, she visited

with her daughter and "bonded" with her infant granddaughter. After she felt rested, Ashley was able to step back into her previous job.

Regardless of disability status, all low-income women who are in "good standing" with social services qualify to receive monthly food stamps. Women must visit their "food stamp worker" twice yearly in order to reassess and verify the need for assistance. Need in this context is based not only on household income and size, but social program enrollment as well. Women must disclose all sources of financial support, including rent subsidies and public health care insurance as a part of the benefits application process. Food subsidy payments ranged from ten dollars for single women with no children and regular income to more than three hundred dollars for women with children[xii]. Women who received only ten dollars per month were categorically low-income, but were enrolled in myriad social programs that alleviated their financial burdens. This distinction was not welcomed by women who, despite their enrollment in programs, still struggled to make ends meet every month. Ten dollars, among many women, was seen as an insult aimed at discouraging women from enrolling in the program altogether. Upon learning that their benefits would not exceed ten dollars per month, some women in this study opted to forgo food stamps altogether.

The paper food stamps of decades past are long gone. In Midway, women carry an "electronic benefits transfer" (EBT) card. Each month, the department of Health and Human services deposits each woman's allotment of "food stamp money" into her EBT account. Once the money has been transferred to the account, women can use their EBT cards like a credit card. While EBT cards are more discrete than their paper counterparts, they do not allow women to ever receive cash back for their purchases[xiii]. EBT cards are in this way officially designed to reduce fraud and the mis-handling of federal money for nutritional assistance (North Carolina Department of Health and Human Services 2009).

Midway's Housing Authority also provided an invaluable source of support for many of the women in this study. While some women lived in public housing projects owned by the Housing Authority, many more sought support through the Section 8 voucher program. Section 8, as the program is popularly known, is a Housing Authority rent subsidy program for very low-income and disabled populations. To qualify, women and their families must be in good standing with the Housing Authority, including that

they have no history of conviction for violent crime or drug related activity. Section 8 participants must also keep all utilities running. If a Section 8 case worker discovers that electricity or water services are disconnected in a Section 8 dwelling, they are required to begin proceedings. Tenants are first given two weeks to find the money they need in order to bring their bills current. If utilities are not restored within two weeks, the tenant faces eviction and dismissal from the Section 8 program.

Once enrolled in Section 8, adults and their families can choose an apartment or home to rent so long as the landlord accepts the Section 8 voucher. Section 8 enables very low-income populations the opportunity to live in private residences as opposed to public housing projects. Rent is based on a sliding scale. Some women paid as little as thirty dollars per month of their rent while others paid as much as $200 per month. The program itself is much in demand. At the time of this research, the waiting list for Section 8 enrollment was two years. New applicants were no longer being accepted.

Of all the programs utilized by women, Medicaid service use was the most widespread. Medicaid provided health insurance for the majority of women in this study. It also provided a means for receiving fee-for-service case management. Medicaid case management differed conceptually from Ryan White case management in one important respect: case managers bill Medicaid directly for each fifteen minute block of time spent with a client. For every four units (one hour) of time spent with clients, case managers are reimbursed $31.50 by Medicaid. The employing organization may charge case managers anywhere from three to seven dollars per hour of service conducted.

The women in this study were well aware of the value of Medicaid health insurance with respect to case management. They were also aware that case managers depended upon clients for their own income. Many women "shopped around" for case managers who would provide them with what they felt was the best possible care. Talks of changing case managers were frequently focused on the availability of a case manager and her or his willingness to "go the extra mile" for a client (Lisa). In this context, the extra mile could mean food pantry shopping for a client, driving a client on errands, or calling a client to see how they have been feeling. The placement of such demands on case managers signified a change in the dynamics between case managers and clients.

In the past, Medicaid case management has functioned much like Ryan White case management. Fee-for-service case managers provided referrals, one-on-one counseling, and made phone calls on behalf of their clients. The last few years in Midway, however, saw a dramatic increase in case management agencies serving Medicaid clients. As the Ryan White dollars available for non-medical case management dwindled and the restrictions for billing Ryan White tightened, many service agencies began solely contracting with Medicaid. In effect, Medicaid case managers "flooded" the market, increasing the competition for clients who had Medicaid insurance. At the time of this research there were seven Medicaid case management agencies in Midway[xiv].

Some women responded to this competition skillfully. Lady E., for example, often changed case managers according to her most immediate needs and the willingness of a case manager to "do what it takes" to win over her "business." The decision to change case managers is not without careful deliberation, however:

> Well right now I'm in the process of changing case managers which can always be really tricky. Because when you pulling money from people's wallets, I find basically in HIV case management that a lot of agencies don't want to take you—will not give you the services that you need because you don't have Medicaid insurance and they can't bill it to be paid. With Medicaid, you now have carte blanch. But I went a year and 6 months with no Medicaid. I have an allegiance to the people who hung in there with me, but at the same time if I find a agency who can service me better, I got to go with that too (Lady E.).

Lady E. acknowledges that "firing" a case manager has a direct impact on their income. She also acknowledges that personal relationships and loyalty factor into women's decisions regarding with who they conduct their case management business. Important also is that Lady E. received a level of service with which she felt comfortable. All of these factors shape the dynamics between case managers and their clients, ultimately operating to stretch the boundaries of service provision so as to include "favors" and "extras" like transportation. For the above discussed reasons, the actual services provided by Medicaid case managers were highly specific to each case management relationship. Officially, however, the program continues to focus on service-coordination, the provision of referrals, and social program enrollment.

The programs, personnel, and procedures described above together form an important part of the institutional context of women's lives. It is, however, an incomplete institutional context as the life experiences of some women in this study will attest in chapters that follow. The legal system, in-patient mental health facilities, and corporations such as rental agencies and local utilities companies all play significant roles in women's experiences of survival with HIV disease. The institutional context described above moreover represents one shared by all of the women in this study who are navigating survival with an infectious, chronic health condition. Their participation in social programs represents an observable strategy that women utilize, albeit in different ways and to different extents, to increase chances for daily life stability, health, and quality of life.

Theorizing The System of Care

In the preceding pages, I have described the HIV system of care with respect to its individual programs and the procedures producing systemic relationships among those programs.   This conceptualization of HIV care as a series of programs and procedures is particularly useful for laying out the landscape of health care and supportive services in Midway. This strategy, however, privileges perspectives concerned with the inner-workings of individual support programs and medical services. Theorizing each program as existing along a continuum of related services necessarily adopts the language of federal policies that provided the impetus for "the system."   Users of "the system" are cast as individuals who conform, to varying extents, to the values embedded in biomedicine and its structures of care. The ways in which users of the system shape and interpret their health care experiences are obscured by this perspective. I thus draw from post-structural critiques of macro-level focused analyses to emphasize that federal HIV/AIDS support programs do not operate independently of social actors. Rather, I emphasize the contingent nature of HIV/AIDS care in Midway.

As Foucault (1978) demonstrates in *The History of Sexuality, Part One*, particular kinds of subjectivities operate as especially dense transfer points for processes of power. Sexual desire and sexual behavior, he argues, became important objects of scientific

knowledge as a way to fulfill the needs of the Catholic Church and the economy. Discourses and practices of "sexuality" provided a means for the subjugation of individual bodies and the control of populations. Sexuality thus became a way of "being known" and controlled through techniques of self-regulation. Ultimately, this "quest for knowledge" concerning sexual desires and behaviors functioned to service state power.

Power, in the Foucauldian sense, is a productive process that is exercised from innumerable social relations (1978:94). In other words, there is no single source of power. It is constituted by the dynamics of social relations, social transformation, and resistance. Power in this sense does more than repress particular social actions. Rather, power is a dynamic and creative process emergent from and constitutive of social relations within a particular social milieu (1978:92). When power is conceptualized as a process anchored in particular social relations, it becomes possible to consider the conditions under which low-income HIV positive women are transformed into particular types of subjects. In turn, it becomes possible to consider that there is no "objective" truth to social subjectivity. Because power is anchored in *particular* social relations, the subjectivities power produces must always be historically and socially specific (1976:97).

For Foucault (1978:105), sexuality is one particular social construction that is used to produce knowledge in the service of economic processes and political structures. Drawing from this insight, I contend that, like sexuality, the production of health-related knowledge and practice is always political and connected to the social locations of social actors. I assert that the *care* of HIV positive Black women can be framed as one of those dense transfer points of which Foucault writes. Women's identities and subjectivities as *HIV service clients* represent another social milieu comprising a transfer point for relations of power.

Bourdieu (1989) defines a social field as a set of objective, historical relations between positions anchored in certain forms of power (Wacquant 1992). The social field is simultaneously a space of conflict and competition in which it is the shape and divisions within the field that are at stake. The social world, in this framework, is comprised of multiple fields (or what he refers to as spheres of play), each with its own particular values and regulative principles. The principles and values of public health programs, for example, create a conceptual space in which social actors struggle,

depending on their social location, either to change or preserve definitions of health and/or care.

The notion of a social field can be used to consider the particular relationships through which HIV health exists as a social process being actively defined through women's relationships to providers of care. Considering that the "boundaries of the field" are at stake in social interaction, I explore women's strategies for navigating programmatic services as a means for changing and/or preserving definitions and processes of care.

Capturing the material conditions and social dynamics experienced by women receiving care and treatment for HIV infection requires adjusting the lenses through which "the system" might be typically viewed. Perhaps first and foremost, the Ryan White public health care program must be understood in relation to the broader political and economic context of neoliberalism in the US. As Goode and Maskovsky (2001) note, neoliberal ideas about the role of the free market in public welfare and economic development are based on an "ideological sleight of hand." Neoliberal ideology depicts the poor as "invisible, passive, pathological, or in need of charity or moral reform…" (Goode and Maskovsky 2001:3). Such a perspective essentially erases the role of capitalist processes and state activity in the production of poverty. This sleight of hand is achieved through racist and sexist representations of the poor that effectively bolster moralizing discourses of the personal responsibility for one's life circumstances.

Within this neoliberal perspective, HIV positive poor women of color are cast as neoliberal subjects in need of behavioral intervention. The "sleight of hand" helps to define federally funded health care programs as a social field aimed at behavioral modification rather than addressing the root causes of impoverishment and ill-health. In this context, the Ryan White CARE Act can be understood as a technology of care that articulates in particular ways with the ideological foundation of neoliberalism.

The Ryan White CARE Act represents an institutional response to the growing epidemic and early activists who called attention to the social and medical injustices faced by persons living with HIV/AIDS (see Cohen 1999; Feldman 1995; Schneider and Stoller 1995; Treichler 1999). In 1990, Congress enacted the Ryan White CARE Act. The Act's title II clause directed financial assistance via the administration of block

grants to individual states and eligible metropolitan areas (EMAs). Grant amounts were based on the cumulative number of HIV cases in relation to the total population of a given state or EMA. Many block grants included stipulations that the state match federal funds for the care of HIV positive populations. In any case, financial assistance was specifically designated for AIDS Drug Assistance Programs and the development, coordination, and operation of systems of the delivery of essential services. Legislators did not define "essential services," but rather left the definition up to individual state governments and their constituents. Leaving open the definition of essential services created great regional and state-by-state variations in what constituted a "system of care." Densely-populated states and EMAs that were hit hard by the epidemic tended to develop a variety of AIDS-related services that complemented clinical trials and regular medical care. Support programs ranged from peer advocacy and case management to massage and acupuncture. Smaller states and/or those with fewer cases of HIV infection (and thus fewer Ryan White dollars) developed much more limited systems of care that would not include "alternative" treatments or support services other than perhaps case management and emergency assistance funds. Subsequent reauthorizations of the CARE Act in 1996 and 2000 re-affirmed the discretion of states to define HIV/AIDS health care services.

By 2006, the landscape of HIV care changed dramatically in response to growing infection rates among poor women of color, poor men of color, and poor rural communities in the US south. As a result, Title II funds were re-directed to the southern states and other hard hit areas left virtually unaddressed by Ryan White legislation. There was, however, another, perhaps more significant change in the terminology of Ryan White legislation. Where before "essential services" or "core services" were left undefined and (in that way) responsive to local conditions of the epidemic, the 2006 re-authorization defined "essential services" exclusively as medical care.

The new and explicit focus on medical care is accompanied by long-standing discourses of medication compliance and treatment adherence. Maskovsky (2005) explores the discourse of adherence as a culturally-constructed, value-laden site of power where medical interventions area linked to social interventions. In his estimation, adherence discourses are part of the "general strategy to promote the role of market forces in developing solutions to health and welfare crises…" (Maskovsky 2005:137).

Questions of treatment adherence displace questions about treatment access and quality, essentially repositioning the onus of blame onto individual "clients." The increased focus on medical care and treatment outcomes in this way mirrors the normalizing and individualizing processes associated with the neoliberal transformation of social programs, such as welfare assistance.

Federally-funded health care programs have always reflected particular political and public health goals. In the context of mounting pressure from activist organizations such as ACT-UP San Francisco and Gay Men's Health Crisis (Jones and Dawson 2001; Treichler 1999), Ryan White funds could be conceived of as the impetus for increasing health care access among a vocal and relatively powerful constituency of care consumers. I argue that Ryan White funds can be understood simultaneously as an impetus for increasing medical treatment adherence among otherwise "non-compliant" individuals. Viewed in this light, the new Ensure oversight measures were meant to cut back on filling "unnecessary" prescriptions. The measure also functioned to guarantee that clients maintained regular contact with their physicians. The advent of the TMA, it seems, has positioned Health Partnership, in part, as a monitor of local HIV positive individuals. Midway's AIDS care system can in this way be understood as a site of power where neoliberal ideals of self-management and individual responsibility transect medical ideals of disease management and personal ideals of compassion.

The articulation of neoliberal imperatives for economic growth with a policy agenda aimed at providing health care and support for disenfranchised, HIV positive populations is an uneasy task. There exists a tension between a broader national context of the government divestment of public services and the popular embrace of consumerism and individual responsibility (Goode and Maskovsky 2001) and the budgetary, conceptual, and ideological growth of federally-funded AIDS care programs. The impact of activists, lobbyists, and advocates on legislative outcomes and ideals of compassionate care in this context cannot be over-estimated. Activist victories in clinical trials regulations, HIV health care legislation, and compassionate service provision highlight the incomplete nature of neoliberal hegemony in relation to state policies.

With this in mind, the present analysis highlights that neoliberal logic and rule are subject to local interpretation, transformation, and/or resistance. Such a perspective

focuses on agency and the autonomy of individuals while maintaining the centrality of structures of oppression to a political economic understanding of survival with HIV disease in urban United States (Bourgois 1996:12). There is neither a totalizing "neoliberal state" nor are there actors who operate outside of "the state" (Das and Poole 2004). This means that the task of anthropologists is to consider how state practices shape and are shaped by everyday life (Das and Poole 2004; Stevenson 2007; Verdery 1995).

This approach to understanding the state as being partially constructed in local settings stands in contrast to previous anthropological work. Earlier anthropological work on the state focuses on seeing "the state" as a process or entity external to, but legible on the local level (see for example Wolf 1984; Scott 1998). Scott (1998:2), for example, defines the modern state as a political and economic entity that seeks to "make a society legible, to arrange the population in ways that simplified the classic state functions of taxation, conscription, and prevention of rebellion." Under his definition, states can be "read" at the local level through population registers, legal discourse, the design of cities, and the organization of transportation, among other strategies. Similar analyses position the state as a political, economic, and territorial entity met with local acts of resistance (see for example Nugent 1995; Wolf 1984). Such work highlights the role of macro-level forces in social transformation. However, this approach to the state precludes an understanding of the impact of social actors and local conditions on state practices and policies.

Given these developments in the anthropology of the state, I illuminate how women's everyday encounters with the care continuum and service employees shape state practices. That "the system" of care is neither static nor wholly constituted by an uninterrupted exercise of neoliberal power becomes strikingly clear. Women's perceptions and strategies for negotiating and resisting the exercise of power over their lives become the keys for understanding the operation and management of "the system." In other words, the strategies employed by women who are navigating survival with HIV disease represent a site for the production of knowledge concerning the incomplete and contingent nature of power associated with neoliberal policy and practice.

Because this analysis emphasizes the interplay between women's experiences of survival and the system of HIV care, I suggest a dialectical understanding of "the system." A dialectical framework of care illuminates not only the "official" structure and content of programmatic services, but also the ways in which women's actions and relationships with service providers shape the implementation and operation of programmatic services. Women and their providers of care are not passive service recipients through which the state exercises power. Rather, they use and shape "the system" and its players in ways that are beneficial to them given their positions within current structures of power and inequality. For this reason, I suggest sustained focus on how women endeavor to use federally-funded AIDS care programs as a "surrogate social network."

I define social network surrogacy as the processes through which women associate with service professionals and organizations as a way to generate beneficial social and economic ties. In contexts where kinship and neighborhood ties may be weak or over-burdened, social actors may compel institutions and institutional representatives to act on behalf of their best interest. These actions may include various forms of financial and psychosocial support. The often provisional and temporary relationships women build through programmatic service utilization are "surrogate social networks," meaning such ties serve as substitutes for networks built through personal relations of obligation and trust.

It is important to note that surrogate social networks are always circumscribed and partially delimited by the policies and protocol of the particular institutions through which they are built. While individual service professionals may become personal social network members, their abilities to draw upon programmatic service resources are defined in the context of the institution. The particular benefits of such a relationship thus remain surrogate in nature.

The notion of a surrogate social network is here used to explore the unofficial and often take-for-granted aspects of AIDS care provision and utilization. Such an approach suggests that health care represents an amalgamation of social relationships in the broader contexts of policy and economy. Such an approach also suggests that what constitutes "the system" is actively defined, stretched, and retracted through the endeavors and

abilities of women to bring care providers into their social networks. "The system" is then here explored as a series of programs and procedures that are responsive to women's needs for strengthened social networks and alternative forms of social capital. Women's abilities to access and embody social capital in this context, however, are shaped by the varying contexts and social positions from which Black women living with HIV struggle for survival.

It is, in part, within the contexts of health care institutions that the women in this study survived with HIV disease. Programmatic services comprised an important, indeed crucial, part of women's resource base and strategies for daily life stability. While individual service programs can be explained in terms of the relationships among program goals and procedures and the policies upon which procedures are based, such an approach cannot fully account for the dynamics of care. Women's community and daily life contexts articulated with programmatic services in particular ways. The context of social network surrogacy, in other words, is a composite social field (Meinert 2004) comprised of a broader city context, women's daily life circumstances, and the ways in which women bring those realities to bear on service utilization.

CHAPTER FOUR:
"IT'S NOT ONE SIZE FITS ALL:" THE COMMUNITY CONTEXT AND INTERSECTIONAL INSIGHTS ON DIFFERENCE AMONG LOW INCOME BLACK WOMEN LIVING WITH HIV DISEASE

Women's daily life stories and survival experiences underscore the common and unique contexts in which HIV positive African American women in Midway grapple with illness. Women discussed their experiences of survival with HIV disease with respect to their personal life conditions, community concerns and experiences, and the institutional conditions under which they navigated the system of care and support services. In all cases, women brought to bear their personal life stories on their interpretations of their health. All interviews focused, at least to some extent, on the personal trials and tribulations women faced. However, these personal trials and tribulations were ultimately shaped by social processes beyond individual control. In this chapter, I consider women's personal trials and tribulations in relation to broader processes of race, class, and gender that structured research participants' community contexts.

Community Experiences of Gender-based Violence

Many women in this study explained how processes of survival began long before they were diagnosed as HIV positive. When I first interviewed Tasha we discussed what it was like to be homeless, the usefulness of Midway's social support programs, and the friends and family members she most relied upon for economic and emotional support. When we finished discussing the topics included on my interview guide, I asked Tasha if there was any other topic she would like to discuss. She quickly responded that, "you didn't ask me how I got it. That's important."

I was taught through previous research experience that asking an HIV positive person how they contracted the virus was tantamount to blaming that individual for infection. Frankly, it was a question that I had learned to consider as being "beside the point." Years of reading scholarly literature on health inequality and political economy had prepared me to perceive how historically-based race, class, and gender processes

structure the distribution of ill-health such that African American women are disproportionately burdened by the risk and realities of HIV infection (see for example Breen 2002; Cohen 1999; Farmer 1996). The particular personal life circumstances of an individual's HIV infection are necessarily shaped by the broader conditions of social life. An analysis of HIV survival, I soon learned, could not focus on women's definitions and experiences of the health without sustained attention to the intersecting contexts in which they struggled for survival (see Connors 1992; DiLeonardo 1991; Ginsburg and Rapp 1995; Morsy 1996).

That day, Tasha described to me vivid and haunting accounts of sexual abuse and rape. She endured years of sexual abuse at the hands of her older brother. She also lived for decades with the haunting memory of being raped in a nearby park by a White stranger who seemed much older than herself. Fearful of retribution, Tasha never shared with her family the realities of the sexual abuse she suffered. Tasha said that, instead, she "kept it secret because she knew they [her family] would blame me." Tasha linked these atrocities and the emotional turmoil they engendered to her subsequent battles with chemical dependency. As she explained,

> I didn't just wake up and say, "Hey, I want to smoke crack." Raped when I was 16, and then I started smoking crack. Out there tricking, selling on that corner, selling my body. And then I got raped again when I was like 39, right on the street. It was a White guy too. So yeah so you know. I didn't call the police because I felt like, "Hey, I'm out there selling to make some money." I figured I was in the wrong. What the hell.

Tasha plainly identified sexual assault as a primary reason for her subsequent battles with addiction. Unfortunately, lived experience of sexual assault was not uncommon among the women with whom I worked. Statements of self-blame were also common among women who suffered abuse. Several women endured the mistreatment of their bodies during youth by family members and strangers. Many women also recalled distressing experiences of domestic abuse as adults.

While women ultimately described HIV infection in terms of their personal biographies, there are broader contexts of which they are a part. Gendered power dynamics and economic processes bolstering racial and gender inequality increase the chances that African American women will be put at risk for unwanted or coerced sexual activity (Farmer 1996; Susser and Stein 2000; Whetten-Goldstein and Nguyen 2002).

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Public health research suggests that intimate partner violence is correlated with sexual coercion (Josephs and Abel 2007; Kane 1998). In other words, women who are physically abused by their sexual and domestic partners are more likely to be coerced into "risky" or unwanted sexual scenarios than women who are not abused by their partners. A lack of economic alternatives (Connors 1996; Kane 1998), feelings of powerlessness (Dixon 1990), and addiction (Connors 1992) complicate women's abilities to leave abusive partners (Jones De-Weever 2005; Whettyn-Goldstein and Nguyen 2002). African American women endure physical violence and sexual assault at a higher rate than women of other ethnic/racial backgrounds. African American women endure physical abuse at a rate that is 35 percent higher than that of their White counterparts (Taft et al. 2008). In the context of intimate partner abuse, lower income is associated with higher levels of abuse (Goodman et al. 2009; Nam and Tolman 2002; Taft et al. 2008) while unprotected sex (Tucker et al. 2006) and HIV infection (Sareen et al. 2009) are associated with having an abusive partner (Fuentes and Mitchell 2008). Midway's community context of HIV infection is shaped by the racial, gender, and class power dynamics that render African American women vulnerable to unwanted and/or coerced sexual activity and physical abuse.

Community Contexts of Economic Hardship

The articulations among economic conditions and HIV infection represent a tightly woven dynamic (Dixon 1990:227) faced collectively by the women in this study. Political economic analyses provide an invaluable conceptual framework for understanding the social processes through which distributions of wealth and power are realized. Here I explore the *lived experiences* of macro-level processes of economic reform outlined in Chapter Two. This approach is intended to illuminate the dialectical relationships between women's personal life biographies and broader community contexts of economic blight and HIV infection as they have unfolded in Midway.

Thirty-four out of forty women interviewed discussed difficult conditions of poverty as life-long challenges. Given the statistical evidence concerning poverty rates among Black Americans in North Carolina, women's explanations of economic hardship

were not surprising. Table 4.1 and Table 4.2, located at the end of the chapter on page 84, provide select population statistics for the total North Carolina population and North Carolina's African American population, in particular. These tables provide the basis for the following discussion of poverty among North Carolina and Midway residents.

As Table 4.1 indicates, African Americans comprise 21.6 percent of the population in North Carolina. African American females represent 53.1 percent of the state's Black population. Table 4.2 illustrates that an estimated 21.7 percent of African American individuals in the state lived below the federal poverty level between 2006 and 2008, as compared to 10.8 percent of the total population. However, the 2000 census reported that African American families represented an alarming 44 percent of the total number of North Carolina families living in poverty at the time (US Census Bureau 2000).

Table 4.2 also indicates that, African Americans, on average, have a higher poverty rate and lower levels of educational attainment than the general population. As a result, Black families earn only 71 percent of the average income reported for the state's total population (U.S. Census 2000).   In Midway, African Americans experienced median income levels that, in 2000, were 31.9 percent lower than the median income and were thirty-three percent more likely than Whites to live in poverty (State Center for Health Statistics 2005).   Study participants' lived experiences of economic inequality reflected a community context in which material deprivation were all but normalized.

Tanya, for example, articulated her life experiences in ways that brought conditions of inequality into stark relief. Tanya was raised as a ward of the state since the age of nine years. After her mother died, she requested to be moved with her half-siblings who were living with their father (Tanya's step-father). When the request was denied by her step-father, Tanya had no choice but to live with her father. Shortly after moving in with him, Tanya's father became physically abusive. She was promptly removed from his home and placed into foster care where she remained until the age of eighteen. After her eighteenth birthday, Tanya was released from state care. She had little money, a low-paying part-time job, and virtually no family on whom she could rely for financial support. Tanya soon met her husband and the two started a family of their own. She was unaware that he had unprotected sex with another woman. As she stated,

I didn't even have a chance at not being poor, really. The HIV was like crazy though. I was shocked at first. He was my husband. I wanted the family I didn't get to have and he seemed like a healthy guy. I didn't think he had it.

Tanya's story represents just one set of life experiences that could be characterized by conditions of long-term impoverishment that shaped conditions of HIV infection. Her personal biography, like those of many women in this study, included a female-headed household as women's families of origin, long-term financial instability, and a turn to state support as a last resort. In North Carolina, roughly 38 percent of African American families are headed by females (see Table 4.2). Of these, nearly thirty-five percent live in poverty, compared to twenty-nine percent of White female-headed households (State Center for Health Statistics 2005).

Although only two women described themselves as having ever been "wards of the state," most women reported that state programs had been an important part of their families of origins' economic strategies. During our conversations concerning economic background and social service use history, women recalled growing up in "the projects" and/or living in households that received some form of public assistance. Women did not tend to recall their thoughts or feelings about state support programs during childhood, although many described childhoods where ingenuity was key to survival. Memories concerning hand-made clothing, outhouses, gardening chores, and/or lack of health care served as points of comparison for women's present conditions. Many regarded their store-bought clothing, indoor plumbing, and public health insurance as proof that they achieved greater stability than their parents. At the same time, however, women noted that they had perhaps fewer resources (such as a backyard) for self-reliance. Women's direct experiences during adulthood and/or late adolescence with non-HIV-related programmatic services such as AFDC provided a critical personal and community context through which they assessed the trajectories and impact of state economic policies and practices on their personal life and social circumstances.

Midway has historically been a city associated with the tobacco industry, textile mills, and a burgeoning Black "middle class." Not unlike many cities across the US upper South, Midway had proven fertile ground for the Black freedom movements of the 1950s and 1960s (Greene 2005:5). Legal and social rights to gainful employment, social

service entitlements, and formal social equality were hard won conditions fought for by Midway's Black residents, wealthy and poor alike. Some of the older women in this study (roughly six women ages 50-68) recalled how intense civil rights struggles led to improvements in living conditions during the 1970s. There were jobs to be had in hosiery mills, denim factories, and in social service offices. Rene, for example, recalled how happy she was as an employee of the Department of Social Services.

> Life before it [HIV] was great. I admit it. My life was fine then. I worked, I had clothes, I had a life. I could buy what I needed. Now I have to bow down a little bit. I can't go spend ten dollars on a set of sheets because I have to worry about some milk I got to buy or some juice I got to buy —something I got buy.

Rene's career as a home health aide for Midway's Department of Social Services represented a time in which African Americans were purposefully integrated into the social service system as employees and consumers (Mullings and Wali 2001; Naples 1998). Prior to this work, Rene had received a modicum of income and nutritional assistance, but found little in the way of support in searching for gainful employment and/or long-term financial stability. During our interview, she described how it felt to put on clean, white pants and a freshly ironed shirt before heading off to work. She laughed when she remembered how passers-by and new acquaintances would mistake her for a nurse. She felt proud that, at one time, strangers thought her to be a medical professional.

By the late-1970s and early 1980s, Rene struggled to make ends meet on a home health aide salary. She remembered these years as "a hardship" because she had become accustomed to paying her own way and even having "a little extra for fun." She began focusing on painful and emotionally-draining thoughts about the sexual abuse she suffered as a child. She drove the thoughts out of her mind by drinking alcohol. Rene learned about smoking crack from a friend and quickly developed an addiction. By the mid 1980s, Rene had tested positive for HIV infection. She tried to commit suicide several times before being involuntarily admitted to an in-patient psychiatric facility. Months later she was released. She lost her job, her apartment, and her social life. Her personal account of HIV infection is, through these experiences, intractably tethered to a community context ultimately shaped by national political and economic trends. Rene's social position with respect to broader processes of poverty, national efforts at social

service expansion, and the subsequent international economic recession of the late 1970s and 1980s (Harvey 2007) increased her chances for ill-health.

Some of the other older women in this study, ages 40 to 68, remembered the 1980s in terms of a different regional context (see appendix 1 for demographic description of study participants). For twelve of the women I interviewed, this decade represented a time of escalating violence, diminished employment opportunities, and accelerated drug-related activity. The women in this group remembered the 1980s as the reason why they left their homes in the urban northeast and came to North Carolina. Lady E. described her reasons why she chose to migrate to the south, despite having no social connections in the region.

> As far as education during the time—well I grew up in Harlem, NY and during the time that I was there, there was a lot of killing and just rampage back in NY. The gangs it was just outrageous. It was in the years before Guiliani cleaned it up. And um it just wasn't a good place to raise kids though I was born and raised there. So I just chose to come to the South.

For Lady E., the decision to come to North Carolina was based on her concern for her children. She had never visited North Carolina prior to the move and did not know anyone there. During our interview, she described how she thought of North Carolina as a "quaint and quiet" place where she could enjoy nature and a better quality of life. Carol Stack (1996) explored the phenomenon of "return migration" among African Americans. She found that disillusionment with urban life in the Northeast coupled with the loss of manufacturing jobs in the region compelled African Americans to return "home." "Home" represented a place where return migrants could strengthen their connections to family, self, and place. Feelings of "belonging" in North Carolina coupled with the desire to escape the chaos that can be associated with urban life framed many women's explanations of why they moved there. However, only four women of twelve identified as persons "returning" to the south. Tamara, Lisa, Danielle and Muriel returned to North Carolina in search of a quieter life that included family they had left behind in their youth. For the other "migrant women," the south simply represented a much needed break from intensifying drug activity in the urban northeast during the 1980s (Bourgois 2003) in a context of growing unemployment rates (Timmer 1994).

Whether women were born and raised in Midway or had migrated to the city with no social connections seemed to matter little in terms of economic stability. Only four of the women in this study considered themselves as having "good jobs" during the 1990s. Two of the women who had well-paying employment before diagnosis with HIV disease lived in other states. Following national trends set into motion by the enactment of the North American Free Trade Agreement, North Carolina's manufacturing plants had begun to move overseas in search of a cheaper labor force. North Carolinians experienced a twenty-seven percent decline in manufacturing jobs between 1990 and 2003. In 2003, more than 60,000 manufacturing jobs were eliminated, concentrated mainly in textile mills and furniture factories (North Carolina Rural Center 2009).

The women in this study struggled to find employment in the "new" local labor markets focused largely on health care, professional and business services, and leisure and hospitality (North Carolina Career Network Resource Center 2009). In part, lack of education eliminated many possibilities for well-paying employment in the new service-oriented economy. Less than 40 percent of African American adults in North Carolina are high school graduates (see Table 2). In this study, half of the women interviewed had obtained a high school diploma or GED. Of the twenty women who had completed high school or its equivalent, only four women worked what they described as a stable, well-paying job during the 1990s.

The four women who had managed to find and keep well-paying employment during the 1990s were later forced out of the labor market due to health conditions. For example, Tamara and Marjorie both worked as secretaries at a large computer firm before they were diagnosed as HIV positive in the late 1990s and early 2000s. Marjorie left the firm prior to diagnosis because her ailing son required around-the-clock care. Tamara, however, worked at her secretarial position until she became ill with HIV infection in 2002. Grace was a school teacher until a sudden and serious stroke left her unable to perform her job in 2006. Charlotte worked in the manufacturing sector of a large pharmaceutical company until she developed an addiction to cocaine in the early to mid-1990s.

For the remaining thirty-six women in this study, well-paying employment opportunities were few and far between during these years. Tasha, for example, worked

in several low-paying and temporary jobs after she was laid off from one of the area's last remaining textile mills. She worked for $5.25 an hour (close to one dollar over the minimum wage at the time) as a baker's assistant at a local bread store. That job was short-lived because she developed chronic diarrhea that kept her from attending to her job tasks at the times she was needed. She could not maintain a consistent work schedule as her manager required. Her next job was as a cashier in a grocery store. At this job she earned only $4.25 an hour. She soon found that, although her wages were not enough to pay her bills, they were enough to have her income assistance and food stamp allotments cut. As a last resort, Tasha began allowing particular individuals to steal items from the store. She would take her "cut" later once she was no longer at work. Tasha was caught enacting this plan. The store manager filed charges against her for larceny. She has been since unable to find employment.

Overall, most of the women in this study had long been what could be considered as peripheral and/or "expendable" actors in local labor markets. They represented the "cheap and deep" labor force engendered by processes associated with accelerated neoliberal economic globalization and a shrinking labor market (Harvey 2005:169). The loss of manufacturing jobs in urban centers created a class of laborers in the city that were ill-equipped to access the new service-oriented market (Susser 1982; Sassen 1996). Thus low-skill jobs were increasingly scarce while the pool of un-employed wage laborers continued to grow. As a result, wages among urban factory workers dramatically declined and benefits such as health insurance were discontinued. Some were able to find permanent, albeit precarious, employment in the "new" economy, but found themselves in low-wage service jobs such as clerical, retail, custodial, and security work as well as in the fast food industry (Timmer 1994:27).

Nationally, employed Black women experienced a decline in wages. The current mandate to work in exchange for welfare benefits exacerbates these conditions (Danziger and Lin 2000; Goode 2002; Morgen and Maskosky 2002; Newman 2001). As Piven (2001) explains, welfare-to-work programs have essentially removed the floor under wages in already low-wage sectors of the labor market economy. The mass movement of welfare recipients into the paid labor force has limited women's abilities to provide for themselves and their families by creating a surplus of low-wage workers and thus the

conditions through which wages are suppressed (Piven 1998, 2001; Henrici 2002). Welfare recipients sometimes work in exchange for their benefits or, in another scenario, women's benefits are given to employers who then pay women less than the minimum wage. Employers receive substantial tax cuts for their participation in the workfare program. As a result, employers have an incentive to "hire" welfare workers. Because of this "privileging" of workfare participants, union workers or workers who have typically received more than the minimum wage are displaced in favor of employing a "cheaper" labor force. This practice ensures that wages stay low even when non welfare-to-work participants are hired (Piven 2001:142-145).

The most readily available employment options for women in Midway with less than a high school education included housekeeping, part-time day labor, and certified nursing assistant. Three women in this study attained their GEDs in the years prior to this research. Many other women had plans to finish high school or to take free courses at the local technical college. Meanwhile, in the absence of significant options for secure, well-paying jobs, many women turned to social services programs for financial and in-kind resources. Twenty out of twenty-seven women who completed secondary interviews had received social services support for a year or longer prior to their diagnoses with HIV disease.

Women with children generally reported that AFDC and food stamp programs often proved insufficient to meet their most basic needs of food, shelter, and personal care items. Women lamented that they were also unable to provide their children with material non-necessities such as new shoes, updated clothing, toys, and other such items that afford children a kind of social capital among their peers (Chin 2001). In the absence of such "cultural requirements," women felt that their children struggled to be socially popular and accepted by peers. Shayna explained that she sometimes felt like she did not give her children enough in terms of material non-necessities. She explained that she felt sorry that they did not have the status symbols they wanted or needed to feel a part of "the in-crowd." She also felt sorry that she was unable to experience the pleasure of giving her children gifts "just because." When her children reached high school, Shayna moved in with her mother in the hopes that the new living arrangement would prove financially beneficial:

> They [welfare] don't give you but the bare [minimum]. And I knew I
> couldn't do it—well when they was babies it wasn't bad. But once they
> got older and I had to buy clothes and all that. That's when I went back
> with my mom because I couldn't do it. And then my mom did like
> Christmas and everything. She took care of us.

Like Shayna, women receiving income assistance checks in the early 1990s found that the older their children grew, the tougher it was to make ends meet on a fixed income. In the absence of fruitful employment opportunities, some women relied upon family members and friends for support. Other women, however, found welfare and social services guidelines to be intolerant of women's strategies for survival and child rearing. Roberts (2003) points out that racial imbalance is pervasive in the foster care system. She argues that Black families face greater challenges than White families in their efforts to comply with state standards for maintaining and regaining custody of children. The end result is that Black children are more likely than White children to be placed into foster care and are less likely to be returned to their families. Chantelle, Jamie, and Christina, for example, were forced to give custody of their children to various family members or face having them legally removed from their homes and placed into foster care. In all three of these cases, women were cited for "neglect" and "abandonment" of children. Jamie, who was still trying to regain custody of her children at the time of this research, explained why she lost custody of her children:

> I had an acquaintance that was saying that I wasn't feeding the kids
> adequately. And you know I had to tell them 'you know with what I
> got and how many children I got, I can't afford to feed them steak
> and baked potatoes.' It used to be that I could split a hotdog between
> two of them and they'd be full. And that worked with what they
> [social services] were giving me. …But, I didn't see an increase when
> my children got bigger and needed more to eat. What might be a
> meal to you, may not be one to me.

Jamie took exception to being labeled as a mother who "neglected" the nutritional needs of her children. She pointed out that the AFDC checks she collected at the time were not enough to cover the expenses of growing children. With no family to whom she might turn, Jamie had no choice but to relinquish custody of her children. Roughly thirteen years later, Jamie was still trying to regain custody of her youngest two kids. The 1996 welfare reform criteria posed a challenge for which she was preparing:

> I think it was a lot easier than it seems to be now. Because the benefits

were more. You didn't have—the last time I was on it—and this was
about twelve or thirteen years ago—they give you a time frame. Now
it's like Workfirst and AFDC and you only get like two years for a
lifetime. If you had a child under six, you weren't required to work.
I guess they look at it as they're giving you something so it shouldn't
be easy. And it's not.

Jamie's previous experience with AFDC shaped her current understanding of income
support programs. She noted that her economic situation was challenging in the past and
was likely to be even more challenging given current reform measures. As described in
Chapter Two, the enactment of PRWORA engendered considerable challenges for poor
women caring for young children. The five year lifetime limit on welfare benefits receipt
represents what becomes a staggering loss of relative stability and autonomy for women
struggling financially. Women are compelled to accept the first job, any job, they can
find. Women with little education and/or marketable skills find themselves in low-skill,
insecure jobs in the service sector that do not offer health insurance or other such
benefits. In Midway, women were most often referred to temporary employment
agencies when they "timed out" of welfare eligibility. For most women "timing out"
occurred when their children were grown. For a few women, "timing out" happened after
the two-year time limit imposed by PRWORA. In either case, women faced a local job
market with little to offer.

In Midway, the meanings of unemployment and underemployment could be
considered with respect to the conditions of women's neighborhoods and the
preponderance of crime in these residential areas. Midway includes three officially
recognized "low-income" zones in addition to city-run housing projects and numerous
middle and high income neighborhoods. The women in this study lived in various
neighborhoods throughout the city. A few women lived in middle income neighborhoods
characterized by single family, owner-occupied housing. The vast majority of women,
however, lived in apartment buildings, boarding houses, housing projects, and/or
duplexes in economically distressed neighborhoods. In either case, women were socially
and institutionally attached to at least one neighborhood characterized by urban blight.
Health Partnership was itself located in a neighborhood designated by the local police as
a "target area" for crime reduction and prevention.

In his "state of the city" address, Midway's mayor acknowledged the continuing need for crime reduction in the city. In 2007, more than 1,100 violent crimes (including rape, homicide, robbery, and aggravated assault) were committed in Midway. Property crimes such as burglary, larceny, and car theft accounted for more than 11,700 reported crimes in that same year. These crime rates, although lower than what is reported for comparably sized cities in the US (such as Montgomery, AL and Baton Rouge, LA), (City of Baton Rouge 2009; City of Montgomery 2008; Federal Bureau of Investigations 2009;) were nonetheless disconcerting to local residents and government.

Formal police efforts began in 2008 to reduce violence crime in particular. "Operation Bullseye," as the crime reduction plan was popularly called, increased police presence and outreach efforts in Midway's neighborhoods experiencing disproportionate crime rates. Police cruisers could often be seen slowly moving down residential streets. When crowds gathered on someone's porch or in someone's yard, a police cruiser was always nearby. The visibility of Midway's law enforcement personnel was a not-so-subtle reminder that communities and individuals were under surveillance.

On two separate occasions, the increased surveillance included "random" traffic check points on the corner adjacent to Health Partnership. I was stopped on one of these occasions and asked to supply my driver's license. The car behind me was driven by an African American male who was a Health Partnership employee. He was also stopped and asked to provide not only his driver's license, but the car registration as well. Many of us sat that day and noticed how frequently young Black men were being stopped at the checkpoint.

One checkpoint stop, in particular, both saddened and excited employees and clients who witnessed the goings on: Police pulled over a red sedan with four young Black men inside. The driver was apparently questioned and asked to provide his license, proof of insurance, and car registration. Next, all of the young men were asked to leave the car. They sat on the curb while police searched the car's interior. After about ten minutes into the stop, the young men were allowed back into the car and to go on their way. Some of the employees remarked that they felt the stop was unfair. After all, several stops had been made that day and this was the first stop that required the passengers to vacate the vehicle. Greg explained that he believed the car was searched

because the passengers were young, Black, and male. He said that, "In this neighborhood, young, Black, and male means gang-banger to the police." Another employee remarked how "sad" it was that young men would have to deal with that kind of stereotype. At that time, a young female client, Tanya, responded that, although she did not think it was fair for young men to bear the brunt of the check point, she appreciated that, "the police are finally doing something. We got gangs everywhere here for real. It's getting to be where if you ain't in one, you're out of luck." Thus despite that crime prevention and reduction activities appeared to operate under racist assumptions, some area residents appreciated the attempts and attention.

The results of this attention, in part, were that the violent crime rate was down more than thirty percent after six months. Homicides and drug offenses, however, were on the rise. Yet, despite some gains with respect to Midway's crime rate, the women in this study reported that violence was intensifying in their neighborhoods. Their explanations of why violence was escalating in their neighborhoods were intimately tied to community conditions concerning the underground drug economy and addiction.

Community Experiences of Drug Addiction and Gang-related Activity

Diminishing options for employment coupled with stressful neighborhood conditions led some of the women in this study to turn to drugs and alcohol as a survival strategy. For other women, drugs and alcohol had already long been a part of their lives. Aside from being an illegal and potentially health-demoting activity, drug use can be a means for social network expansion and material comfort in contexts of severe and chronic deprivation (Pivnick 1993; Singer 1991). Drug addiction literature suggests that poor women of color utilize illicit substances as a form of self-medication. Self-medication, in this context, can include drug use with the intent of eliminating feelings of stress and numbing painful memories (Connors 1992; Ward 1993). In other cases, drug use habits represent one way that women can gain the economic and emotional support of a male partner (Connors 1996; Fullilove et al. 1990; Sobo 1999). Whatever their motivations, the women in this study collectively faced a community context in which chemical dependency was rampant.

Twenty-five out of forty women identified as either being in "active addiction" or "in recovery." Crack was, for the most, women's "substance of choice." Yet, given the political landscape along which crack entered US inner-city neighborhoods (Bourgois 2003) and the economic conditions under which crack sales and use proliferate (Mullings 2003), it is difficult to attribute "choice" to this process. A small "rock" of crack-cocaine is relatively inexpensive, rendering it an attractive option for poor women who are addicted to drugs. Its highly-addictive nature, however, often means that crack use escalates rather quickly and can be, in that way, very costly.

Some women, such as Charlotte and Rene, had achieved long-term recovery by abstaining from alcohol and drug use for five years or more. Other women who self-identified as being "addicted to drugs" had varying results with recovery goals. For example, Lady E. achieved 180 days "sober" during the research year. After two previous attempts at sustained sobriety, she was enthused and proud of the success she was having. Jamie, however, struggled on an hour-by-hour basis. During our first interview, Jamie discussed that she had five hours "clean." She explained that, "five hours may not seem like a lot to you, but to me it's a lot." When I asked her if there were certain things that triggered her cravings, she responded with a story that drew connections among her experiences of poverty, addiction, and neighborhood distress.

Jamie grew up in what she described as a stable family that worked hard for the few things they had. Jamie fell in love while she was young and had five children with her "first love." When they separated, Jamie became a single head of household without employment. To offset their hardship, Jamie moved her family into a local housing project. Jamie soon began smoking crack, occasionally at first, as a form of social activity with friends and neighbors. Under these conditions, she fell in love with a man who was HIV positive. Jamie was unaware of his status until she discovered AZT in his medicine cabinet. She promptly went for her own HIV test and learned that she too tested positive for the virus. This knowledge, she explained, intensified her addiction and led to long-term depression:

> It [the virus] made my drug use increase because—I don't know how much you know about crack, but it's like an upper. So the days that I could not function, I had my children and they got home from school and I had to function. So I would get high just to get through. And

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then it also helped me forget that I had this disease.

Since the escalation of her drug use habits in 2000, Jamie has been unable to abstain from smoking crack for more than a few days at a time. At first she believed that "coming to terms" with her HIV infection would necessarily curb her cravings. She feels as though she has accepted HIV as a part of her life, but still struggles to quit. Despite her regular attendance at addiction support groups and an earnest desire to achieve long-term recovery, Jamie faces a kind of geographical obstacle for meeting her goal. Her neighborhood was one of the drug "hot spots" in Midway. She explained during our interview how her latest attempt at sobriety was thwarted by a neighbor:

> I have days where I don't think about using. It just so happens up until like 6:30 this morning—because if it wasn't for them knocking on my door and me answering it—I would have three days clean. But, it was someone that knew that we had gotten high—that we had bought from in the past. And it was free. That time. But I think that his sole purpose was to get me back into it.

Jamie's experience with having a drug dealer offer her a "free taste" was not uncommon among the women in this study. In some ways, the concentration of impoverished individuals and families were viewed as "fertile ground" for dealers. Greg, a Health Partnership employee who lived in Midway, explained that:

> It's fucked up. I know some of these dudes who just walk up and down the streets in the projects. They just knock on people's doors and give them drugs if they won't buy them. They're just looking to make a buck and they make mad cash. It's sad because I'll see like one of "my boys" go into the projects and then I see like who he sold to at the end of the month when they don't have money for their rent.

As Greg described, Midway's fourteen housing projects and various low-income neighborhoods are targeted by drug dealers as areas for the sale and distribution of their goods. Some of Greg's personal friends sold drugs in the neighborhoods where Health Partnership clients lived. Greg always "knew" who his friends sold drugs to at the end of the month when he met with clients needing financial assistance. Women such as Jamie who have used drugs in the past may find it difficult to tell a dealer "no" when they are being offered drugs for free. Kareese had similar experiences with dealers in her neighborhood. She finally posted a sign on her door to warn drug dealers that, if they approached her stoop, she would call the police. Although this action helped to keep

dealers at bay, she was verbally harassed on a regular basis when she walked through the parking lot to the bus stop.

Neighborhood violence affected women regardless of whether they were in active addiction or not. The violence that can accompany drug-related activities and transactions was at the forefront of women's experiences of community, even when those experiences were, for the most part, positive. When asked about what they liked best about their neighborhoods and the city, most women described the benefits of living close to relatives, their church communities, and local resources for free recreation. The city and community-based agencies often sponsored community celebrations, health fairs, free classes, and free "sneak previews" of university theater productions. Many women also had close bonds with family and fond memories of growing up in Midway. Other women compared Midway to larger cities such as New York. Midway often compared favorably because the "pace of life" was slower and the air seemed "fresh."

However, when asked to talk about what they did not like about Midway or their neighborhoods, women shared frightening stories of gang-related violence. Harvey (2007:171) explains that neoliberal economic policy and practice have essentially stripped poor and near poor populations of the economic conditions and social institutions needed to relieve the financial burdens of the poor, create social bonds, and facilitate collective endeavors to improve the position of laborers in the social order. Alternative social forms can fill this void in the form of gangs, criminal cartels, and mini-mafias (see also Mullings 2003). While the vast majority of Midway residents and Health Partnership clients do not participate in gangs or criminal cartels, they are subject to the destruction that such social forms can engender.

In Midway, discussions of local gangs and gang-related activity were always accompanied by stories of violence. Many of these stories were unrelated to women personally, but were nonetheless important circumstances shaping their community contexts. Kareese shared one such story of violence during our second interview:

> Some guys up the street started it. They drug dealers. And then these
> other guys came by with a drive by. So I believe that car was looking
> for the dudes up the street. There's a red gang. Ok up the hill, they the
> blue—the blue ones. I mean they crips. And the reds are at the bottom
> or the projects. I live in the middle of both them.   And all I knew was
> we was on the front porch playing cards and I felt something warm and

then it hadn't even hit my eye yet and I'm like, 'it kinda hot. Let's go in.' And he was playing his cards—he was playing for nickels and pennies. He happened to look up and he said, 'Kareese, you bleeding.'

While playing cards on her porch that day, Kareese was grazed by a bullet. She pointed to the elongated scab across the top of her head as she told the story. Her hair was slightly singed around the spot where skin had been before the bullet skimmed her head. She repeated to me that she was "not scared or nothing" because such occurrences were frequent in her neighborhood and she had become, in a way, de-sensitized to the sound of guns being fired.

Kareese's particular apartment complex was a kind of "no man's land" between the territories associated with two rival gangs. In a surprising twist, the territories are only "socially" separate. They are both geographically and technically part of the same public housing complex owned by Midway's Housing Authority. The gangs, it seemed, frequently fought over which group was allowed to sell drugs to residents of the housing complex and in nearby communities. Women living in other low-income neighborhoods reported similar types of violence disturbances as a regular part of their community context.

Marjorie also lived with the violence engendered by gang warfare and the underground drug economy. When asked what she disliked about her neighborhood, Marjorie immediately brought up the subject of violence within her community and her apartment complex. She attributed most of the violence that occurred in her neighborhood to rivaling gangs who sought to control local markets for the sale of illicit drugs. When local police suggested that area residents "take back their neighborhood," Marjorie grew angry. She explained the story during our first interview:

> We had a problem with the drug dealers hiding drugs on the back of people's porches. The lady next door to me, she had a couch on her back porch. In the summer time it was nice you know the kids would go back there and sit on the couch. Well the drug dealers started using the couches for their little stash spot. So the police came and they knocked on our doors. And we didn't know it, but they was using our grill as a drug hideaway. And the police came and they was like 'you know we just found drugs on the back porch.' I was like, 'why would I hide them outside?' The police was like 'well you all need to take back your neighborhood. Tell them to leave your porch alone.' I am sorry. I am not taking a bullet for that.

Marjorie was outraged that the police would construct the drug dealing problem as an issue to be handled by "neighborhood watch" programs. The potential for danger was a major impediment for women who might otherwise feel compelled to "stand up" to those who would bring drugs, guns, and violence into their community spaces. Kareese, for example, barred a woman from her apartment because she spoke to the police following a drive-by shooting. Kareese feared being seen as a collaborator with police. She barred the woman to prevent her involvement with potential retribution.

Marjorie also reiterated her feelings concerning potential danger by sharing with me a recent story of violence reminiscent of such atrocities as the Columbine shootings.

> There was one night a guy came. I mean actually walking down the street with an assault rifle and he was shooting at these guys who were gang members and if it was not for the brick wall being around my house—he shot the brick wall. He was just walking with his rifle and shooting. My room—the rooms downstairs—bullets would have been all in there. A little girl got killed out there. She was in the bedroom and a guy come through there shooting. It went through the window and hit her. Baby dead.

Marjorie's fear of violent retaliation, should she try to "take her community back," were not unfounded. Given that gunshots were a common sound in her apartment complex, her hesitation to get involved was prudent. Given that she has experienced the terror engendered by an indiscriminate shooter, her hesitation was entirely understandable. Even though women such as Kareese and Marjorie may not be directly related to shootings and other such forms of violence in their neighborhoods, the potential for danger and physical harm are ever-present in their lives.

Women's experiences with ubiquitous and violent crime, physical and sexual abuse, economic hardship, and drug addiction represent a few of the difficult challenges shaping local community contexts. Though women shared with me their personal stories of hardship and survival, their experiences spoke more broadly to lived realities of racial and gender social class formations that are engendered by historical and contemporary inequality. These broader community contexts do not define women's experiences of HIV survival, however. The institutional context of women's lives represents another nexus for the broader social processes brought to bear at the levels of the personal biography and the community context.

An Analytical Note: Intersectionality Theory, Institutional Context, and "Coding" Data for the Production of Difference

Although the women in this study shared the challenges of a community context shaped by the conditions of social inequality, they brought varying skills and resources to bear on their interpretations and experiences of HIV disease. I argue that the ways in which their skills and resources articulated with service provision guidelines and mandates, described in Chapters Three, Five, and Six, produced social differences among women who are otherwise homogenized in many discussions of HIV care and related services. Thinking through the production and maintenance of difference in relation to women's experiences of survival with the virus is a central concern of this dissertation. Such an examination necessarily calls into question the analytical techniques through which "difference" can be imagined and illuminated in this context.

In utilizing an intersectional approach to social research, I paid particular attention to one critique of intersectionality theory. First, critics of the framework suggest that intersectionality theory constructs Black women as the quintessential site of difference (Nash 2008). Nash (2008) argues that white men provide the tacit norm against which the lived experiences of Black women are considered as unjust because the approach is inherently comparative. In other words, it is the implied juxtaposition of White men and Black women that allows scholars to talk about the "otherness" that intersectionality theory seeks to illuminate. Such critiques do not take into account that discourses based in White male normativity are precisely what intersectionality theorists seek to subvert. That critics assume this tacit norm in their readings of intersectional experience justifies the development of a Black feminist theoretical framework as an intellectual project. However, I focus here on differences among African American women and the social processes by which those differences are produced. The analytical techniques employed represent an intentional commitment to avoid, as much as possible, the pitfalls of methodological essentialism[xv].

The community context in which women strove for health and stability are often regarded by policy-makers and service providers as the primary context structuring chances for health and illness. Women contended with federal policies intended to reach a majority of the population. This meant that program employees were rarely able to

tailor service strategies to individual needs. This meant that programmatic procedures were sometimes based on inaccurate assumptions concerning their educational levels, work histories, sexual practices, drug use histories, interests, social lives, and financial circumstances. Programmatic services are necessarily broad when it comes to envisioning a target group, however. While a broad approach can foster inclusion, it also can obscure the dynamic interplay between women's personal biographies and community contexts.

It is under the conditions of daily life circumstances that federally-funded AIDS care in Midway operated as a social process through which women were differently positioned to realize health and well-being. From this point on, I utilize categorical labels to refer to groupings of women within the study sample. These labels refer to women's social and economic circumstances to highlight the differences among them (please see Appendix 2). Labels include "stable women," "temporarily (un)stable women," and "vulnerable women."

The label "stable women" refers to the economic stability enjoyed by some women in this study. The women in this group have long-term housing supported by legal entitlement to remain on the property (i.e. a lease or deed in their name).   Stable women also enjoyed more "disposable income" relative to other women in the study. On average, stable women earned more than $950 per month, with five women earning more than $1000 per month. A key factor in stable women's economic stability was that the women in this group tended to have a variety of income sources, including family. Using a combination of employment, Social Security Disability Insurance, pension funds, survivor's benefits, and inheritance meant that, should a problem arise with one source of income, another was available to meet short-term needs. In addition each stable woman's rental payment was no more than 30 percent of her income. Stable women also reported either long-term recovery (5 years or more) from substance abuse or no prior history of substance abuse.

The categorical label, "temporarily unstable" illuminates the struggle some women faced in trying to achieve and maintain economic stability. In this group, daily life stability was often short-lived during the study period, lasting only two or three months at a time. Temporarily (un)stable women rented apartments and houses in their

own names. While they were legally entitled to remain on the property, this entitlement was challenged by an intermittent inability to pay rent. Most women in this group had subsidized housing. Rent subsidies ensured that many women did not pay more than 30 percent of their income for their housing. However, even with rent subsidies, temporarily (un)stable women strategized for other monthly expenses with considerably less available money than their stable counters. On average, temporarily (un)stable women earned approximately $700 per month. There was considerable range in income, however, with some women earning as little as $546 a month after garnishments and some women earning as much as $930 per month. Sources of income for members of this group were largely confined to employment and Social Security Disability Insurance. As such, the loss of one source of income, even if partial or temporary, was devastating to the household budget. Finally, most temporarily (un)stable women were in varying stages of substance abuse recovery. Periods of recovery for most women in this group ranged from 180 days to five hours at the time of primary interviews. Some women, however, achieved sobriety more than ten years prior to the fieldwork or had never used drugs.

Finally, the category of "vulnerable women" was created to highlight the dire circumstances faced by some women in this study. Although all of the women in this study can be considered as vulnerable in relation to their low-incomes and health statuses, vulnerability was compounded by the living conditions of women in this group. Vulnerable women were all homeless, having no legal rights to remain on any premises, or were in danger of eviction because they had no income to pay their rent. Most of the women in this group had zero income to meet their needs. Two vulnerable women generated income through Social Security Disability Insurance. However, histories of felony conviction and active drug addiction rendered their incomes as superfluous to their efforts to secure an apartment lease. Almost all vulnerable women struggled with drug addiction, incarceration, and/or mental health issues to such an extent that their economic and social viability were impeded.

It is in the context of women's broader socioeconomic circumstances that I focus on women's abilities to navigate institutional networks and survival with HIV disease. I consider how socioeconomic differences matter for building social networks and for programmatic services utilization. In turn, I examine how programmatic services and

social networks affect socioeconomic circumstances. It is thus the confluence of socioeconomic circumstances and institutional context through which processes of survival with HIV disease can be discerned. As such, women's positionalities as programmatic service participants are here considered in relation to their experiences of health. I juxtapose women's year-long trajectories of survival with HIV disease against their abilities to negotiate, maintain, and/or improve the social and economic conditions they sought to address through the strategic use of institutional networks of care.

I consider the institutional network experiences described by women in terms of process. I draw from Gibson-Graham's (1996) notion of class as process rather than class as a social group in order to find and elucidate group-level distinctions among low-income Black women living with HIV disease. While some analysts conceive of class in terms of a population's income in relation to the Federal Poverty Line, I understand and conceptualize class a social process that constitutes and is constituted by processes of health. Thus the distinctions I draw among the women in this study are done so, in part, through the lens of one particular moment of the class process. This "moment" is AIDS-related programmatic services utilization.

Social researchers cannot presume their participants possess certain class interests or class capacities (Gibson-Graham 1996:70). Class analysis must focus instead on how social actors participate in capitalist class processes in varying social contexts. This perspective attends to the reality that individuals may participate in a variety of class processes and from a variety of class positions (Amariglio, Resnick, and Wolff 1988:490). For example, some of the women in this study produced surplus value[xvi] for their employers while they extracted labor in the form of "personal favors" from social service professionals. Other women in this study were self-employed entrepreneurs while simultaneously exploited as uncompensated reproductive laborers in the home and/or community. Still other women struggled to even plan for a future where they might participate in the labor market. Their statuses as chronically unemployed impeded their class process participation in multiple contexts. In any case, women's participation in processes of class was mediated by their social circumstances and strategies for participation in the local care continuum.

In this context, I consider Health Partnership as a nexus through which women participate in, consolidate, contest, and transform their social positions. As Charlotte so aptly stated, "It's not one size fits all here. You have to work at this to make it work for you." The "work" of which Charlotte speaks became a focal point for analyzing women's agencies and strategies for socioeconomic advancement in the context of HIV care.

Conceptualizing how "difference" was produced and maintained in the context of federally-funded health care services required particular analytical attention to women's performances of class and the impact of those performances on living conditions and health needs. As such, the following chapters draw from social scientific notions of biopower and social capital.

Although Foucault refutes the usefulness of class analysis, the concept of biopower is useful in this context. Foucault (1978:140-141) asserts that the sovereign power of the state has been replaced by administrative bodies whose charge is the calculated management of life. The era of "biopower," as he describes, is characterized by the state's indirect power over persons and bodies. This indirect power is achieved through the creation and implementation of "techniques for achieving the subjugation of other bodies and the control of populations" (1978:140). As I analyzed the data for this dissertation, I considered the ways in which Health Partnership might function as a technique of state control over the lives of poor women of color.

Simultaneously, however, I considered the ways in which the women in this study used such strategies as a means for realizing relationships of social and economic value. I explore women's efforts and tactics for the negotiation of health processes as a process that is intractably tethered to the performance of social capital. Women's definitions of and efforts to secure and/or maintain social capital are examined for what they reveal about the dynamics of care in Midway as well as class processes more generally. I further draw from this definition to consider how women actively challenge and/or maintain their relative social positions within local structures of care. "Difference," as I demonstrate in the following chapters, can be discerned in terms of the material conditions of women's daily lives, their socioeconomic positions in relation to local structures of care, and the health needs they articulate in relation to their social positions.

Table 4.1: North Carolina Population by Sex and Age (U.S. Census Bureau 2009)

Subject	Total Population	Black or African American Population	African American Percent of Total
Population number	**9,036,449**	**1,917,297**	**21.2**
Sex			
Male	48.9%	46.9%	
Female	51.1%	53.1	
18 years and older			
Male	48.2%	45.4%	
Female	51.8%	54.6%	

Table 4.2: Selected North Carolina Demographic Characteristics (U.S. Census Bureau 2009)

Subject	Total Population	Black or African American Population	African American Percent of Total	Study Population
Households by Type				
Households	3,533,366	730,109	20.6%	40
Married Couple Family	49.4%	30.5%		20%
With own children under 18 years	20.4%	13.3%		5%
Female Householder, no husband present	13%	28.2%		80%
With own children under 18 years	7.9%	17.9%		17.5%
Marital Status				
Female 15 years and over	**3,721,675**	**808,037**	**21.7**	
Now married, except separated	49.4%	29.5%		20%
Widowed	10.2%	10.1%		10%
Divorced	11.3%	12.7%		17.5%
Separated	3.6%	5.9%		5%
Never Married	25.5%	41.9%		47.5%
Educational Attainment				
Population 25 years and older	**5,964,892**	**1,169,811**	**19.6**	**40**
Less than High School diploma	17.1%	21%		50%
High School Graduate, includes GED	28.9%	33.9%		50%
Some college or associates degree	28.4%	29%		10%
Bachelors Degree	17.1%	11.4%		5%

Table 4.2 Continued

Subject	Total Population	Black or African American Population	African American Percent of Total	Study Population
Poverty Rates for Families and Individuals				
All families	10.8%	21.7%		100%
With related children under 18 years	16.8%	29.2%		n/a
Married couple Families	4.9%	6.6%		**n/a**
with related children under 18 years	6.8%	7.8%		**n/a**
Female Householder, no husband present	31.6%	38.1		**n/a**
With Children under 18 years	39.7%	45%		**n/a**
Housing Tenure				
Occupied Housing Units	**3,533,366**	**730,109**	**20.7**	**n/a**
Owner-occupied housing	68.1%	49.1%		n/a
Renter-occupied housing	31.9%	50.9%		n/a
Gross Rent as a Percentage of Household Income				**n/a**
Occupied Renter units	**1,014,701**	**342,900**	**33.8%**	**n/a**
Less than 30 percent	53%	45.2%		**n/a**
30 percent or more	47%	54.8%		**n/a**

CHAPTER FIVE:
THE SOCIAL AND MATERIAL CONDITIONS OF DIFFERENCE

Across the board, the women in this study struggled to make ends meet each month. The types of material needs study participants struggled with, however, varied according to the daily life conditions under which they strove for stability and financial security. In this chapter, I employ the distinctions drawn among women in Chapter Four (see appendix 2 for a chart of participants) to illuminate the variability of living conditions among study participants. Some women struggled to afford food, find housing, and keep their utilities running. Some women struggled to find money for transportation, cleaning supplies, and Laundromat services. Still some women struggled to keep their cars running and legal, their computers up-to-date, and their educational tuition and fees paid. In all instances, it was the confluence of economic factors that shaped the realities of women's daily lives.

The Material Circumstances of "Temporary (In) Stability"

Fifty percent of the women in this study are here considered as "temporarily (un)stable." Women in this group, although housed and enrolled in income support programs, coped with persistent fluctuations in monthly resources. The relatively high proportions of income they spent on monthly rental payments, coupled with fewer actual sources of support, meant that women frequently carried a portion of each month's bills over into the next month. This strategy, although viable in the short-term, usually meant that the women in this group periodically faced eviction, disconnection of utilities, and/or other similar crises. As such, their needs and living conditions changed frequently and suddenly. Women often responded to questions about their financial circumstances that they were "doing fine at the moment," or were "not too good this week." Their responses almost always included a reference to the present as an indication that their situations could change or had recently changed. Fluctuating daily life circumstances shaped the ways in which women defined and endeavored to meet their needs.

Of all research participants, women living under conditions of temporary (in)stability tended to emphasize the broadest range of material needs and struggles with monthly income. Although women in such circumstances qualified for a variety of social programs outside the system of HIV care, they often had trouble coordinating the technical demands of service eligibility rules and procedures. Enrollment and continuing eligibility protocols can be daunting tasks for women who are only precariously stable because they require the keeping of documentation and maintenance of appointment schedules under already chaotic conditions. Facing the daily burdens of affording food, shelter, and other such basic provisions on a small income can make a seemingly simple task such as completion of paperwork feel like one more obstacle to be overcome.

Tanya was a twenty-six year old mother of seven for whom the tasks of daily life and household maintenance were overwhelming. When we first met, she was four months pregnant. She would not find out until labor and delivery that she was pregnant with twins. Tanya also had full custody of four of her other children. She complained often of the debilitating fatigue she attributed to HIV infection. On a daily basis, she fought the fatigue in order to care for her children. Laundry, meal preparation, discipline, minor injuries, physician appointments, informal income generation, and PTA activities were all matters that filled Tanya's daily schedule from morning until night. To intensify an already overwhelming schedule, Tanya was anxious about her baby's potential health problems. She felt that she had been lucky to give birth to five HIV-negative children. Tanya feared that she would not be so lucky with this pregnancy.

Together with her husband and children, Tanya lived in what she described as "almost total chaos." The family shared a three bedroom housing project apartment on the outskirts of town. Tanya's husband, who is also HIV positive, suffered from depression and occasional bouts of frustration and anger. The emotional turmoil he faced made it difficult for him to maintain regular employment. Tanya struggled under these conditions to satisfy her family's needs. As she described their financial situation in January 2008,

> It's tight sometimes. The kids need stuff. I don't have a light bill or any
> of that stuff though. I don't have any rent. I got HUD housing so they
> pay my rent. I have zero income officially. I do that tutoring on the side,
> but I don't have to pay any taxes on it so it shows up as zero income.

That's how I wash clothes, get detergent, buy those extra things you know.
So it's like $80 or $100 a month that I bring in. I make money (Tanya).

Tanya was technically able to make ends meet through a public housing program,
informal income generation, WIC vouchers, and the additional $425 she received every
month in food stamps. She needed more income support for "extras" such as clothing,
telephone service, personal care items, and educational toys for her youngest children.
TANF was one option that Tanya had exhausted and now sorely missed. Tanya had
already used her lifetime limit of five years eligibility for TANF. However, her status as
a pregnant, former ward of the state with four small children already positioned her to
receive "extra" social services support. Yet, Tanya could not figure out how to make her
claim for "extra" support. As she described,

> They make it really hard for you to get that. You got to have birth
> certificates, IDs. You got to have all that for each child and for yourself.
> I have it for my kids, but I don't have a birth certificate for me. It's in NJ
> somewhere. I don't have any idea how to get a hold of that and prove to
> them that I'm me requesting it. The lady told me that I had to have a birth
> certificate before they could process my application. I'm like are you
> kidding? I was a ward of the state. I been getting welfare, Medicaid, and
> food stamps in this state since I was ten years old. I just don't have the
> the time to run around everywhere for this (Tanya).

  Tanya explained that she felt the technical demands of social program enrollment were
demanding and seemingly inefficient. Many women like Tanya who lived under only
precariously stable conditions did without some of the support to which they were
technically entitled specifically because they did not want the added burden of adhering
to programmatic service rules and regulations. "Doing without" a programmatic service
in this scenario was a strategy for avoiding time-consuming and sometimes emotionally
taxing enrollment and eligibility maintenance procedures.

Given women's decisions to forgo the full range of programmatic services, many
temporarily (un)stable women lived in challenging, if not dangerous, housing conditions.
Although technically "housed" because they were loosely protected by rental contracts,
women's homes lacked many of the features associated with quality housing and
maintaining health. Temporarily (un)stable women did without such household items as
refrigerators, working stoves and ovens, furniture, and, in a couple of cases, kitchen
utensils. In these cases women "made do" the best way they could devise. Make-shift

furniture, plastic utensils from local fast food restaurants, and large appliances covered over with tattered sheets and picture frames were tell tale signs of women's struggles to accumulate the material convenience items taken for granted in many American homes.

As Tanya's lived experiences of survival continued to unfold throughout the research year, her living conditions were further complicated by a lack of necessities and income-earning opportunities. Tanya improvised as best she could when she, her husband, and her (now) six children were evicted from public housing in June 2008 because they could not afford to keep their utilities running. Social services did assist the family with a deposit and first month's rent for a new, unsubsidized apartment. However, Tanya's meager income she earned at the time as a part-time cleaning woman meant that they could not afford much. The family, after a hasty storm of relocation preparation, moved into an apartment that did not have a refrigerator or a stove. Within one week of moving, Tanya found closer to full-time employment as a cashier at Taco Bell. She managed to scrape together the money for a stove, but, five months after the move, still did not have a refrigerator.

The wages Tanya earned as a cashier at Taco Bell were just enough to pay rent and utilities. At $6.75 per hour and roughly $930 per month, Tanya barely kept her family of eight afloat supplementing her income with food stamps, clothing donations, and food pantries. The added burden of having to live with no refrigerator was, by this point, "so ridiculous that [she] just can't even care." Tanya coped with this condition by keeping perishable food in a cooler, buying small portions, and returning to the store frequently throughout the week. In the end, having no refrigerator cost Tanya money that she did not have to spare. She spent more money on transportation to the grocery and she frequently lost food that might otherwise have been eaten as leftovers or stored in the freezer for later use. As she described her abilities to cope with recent misfortune,

> I can jump in there and work. I'll probably keep us all afloat, but as far as getting us back to the shore—I swim like a rock—better hope I can just float here.

Tanya described her recent foray into the food service industry employment in terms of "jumping in" the water. The shore, in her estimation, represents a time where she, her husband, and her children enjoyed greater stability afforded by social programs such as public housing and TANF. After being disqualified from those services, her only

"choice" was to work, however low the wages and unstable the hours. This strategy, indeed the strategy given preference by social program guidelines, felt like sinking more than swimming. Tanya felt her only recourse was to hope that she can "get by" until something better came along such as a new apartment or a better job opportunity. In general, however, women did not experience much luck in terms of finding new or improved housing that fit their budgets. While many temporarily (un)stable women frequently moved into new apartments, the moves could often be considered as lateral.

Temporarily (un)stable women continuously sought long-term housing situations, most of the time sacrificing either the quality of their housing or the safety of their neighborhoods. Lessa described her housing situation as follows,

> My apartment--It's ok. That's a lot of roaches on the move, but I deal with it. Yeah, I called the landlord, but my lease is up so I'm trying to move. I working with a case manager to get a new place that don't have no roaches. …Only place I can afford though is in that nasty part of town that I don't be trying to go to no more. I don't know what I'm going to do yet.

The decision to move from an unsanitary apartment in a more desirable part of town to a more sanitary apartment in an undesirable part of town was a serious conundrum for women. In either case, women felt "stressed out" by their living conditions and their inability to afford to rent a clean apartment and live in a safe neighborhood. Temporarily (un)stable women tended to sign short-term six month leases so that they would have the option of moving if conditions were too rough. Some women also moved out of their apartments before their leases ended without contacting their landlords or paying early move-out penalties, a decision that further complicated their abilities to find quality housing.

Whatever their leasing arrangements, temporarily (un)stable women's houses and apartments tended to stray from what was considered as "healthy housing[xvii]" by Health Partnership staff. Pests such as cockroaches and mice, along with mold, threatened to create or exacerbate respiratory issues among many women and their loved ones. For example, although I sometimes drove her home after a long day at work and Health Partnership food pantry, Marjorie would never allow me to visit with her in her apartment. On most days, Marjorie talked about how she was uncomfortable bringing a "white girl" into "the hood." She would laugh and then tell me to roll up my car

windows, lock the doors, and "keep rolling until you're on the main road." Although I

accepted this response, she always apologized and reiterated that, "*I* don't even want to

go in there."

The eight unit complex in which Marjorie lived with her two young sons sat in the

middle of a large gravel parking lot just off of one of Midway's main highways. The

immediate surroundings included zero trees, no grass, and certainly no flowers of any

sort. The front of the building was concealed by a brick wall that had been chipped away

by years of neglect and more recent gang-related shootings. I never saw the inside of one

of these apartments, but I imagined that they might be in need of repair. Marjorie

described the quality of her public housing complex in this way:

> It's like the cracks all the way around the wall is black. That's all you
> see is black. It's schools and schools of roaches. Right in the corners
> big clumps of roaches. Everywhere they're crawling up and down the
> wall. Everywhere. That is a health hazard. You can't have nobody
> staying in nothing like this.

Even though Marjorie feared for herself and her sons in this unsanitary environment, she

had no choice but to remain in this particular apartment. Her disqualification long ago

from Section 8, discussed in Chapter three, coupled with only sporadic opportunities for

work meant that Marjorie had no choice but to remain in public housing. Anecdotally,

public housing officials seldom granted transfer requests unless the family size increased.

There simply was not enough quality public housing to accommodate Midway's low-

income individuals and families. The logistics of granting transfer requests and keeping

track of new program participant housing assignments was simply unmanageable for

service employees who already had hundreds, if not thousands, of participants on their

enrollment rosters.

While few temporarily (un)stable women could boast having a clean and

affordable apartment *and* a safe neighborhood in which to live, they often described how

they "loved" their homes. This "love" was almost always compared to women's past

experiences of being homeless or of living with relatives who either feared HIV infection

or who did not know of HIV infection. Indeed many temporarily (un)stable women have

dealt with the disappointments and surprises that accompany disclosure of health status to

loved ones. Having an apartment or house of one's own afforded some women a safe

space to which they returned after loved ones rejected them following disclosure of HIV positive status. In other cases, moving into and maintaining one's own apartment enabled women to take another step towards stability and living well with HIV disease. One's own apartment afforded women a sense of "just having your life somewhat together and, you know, being like you can take care of yourself" (Noelle). One's status as "housed," however, did not necessarily mean that women enjoyed income stability or efficacy.

In addition to material needs and housing quality, temporarily (un)stable women frequently lamented the small stipends they received as income assistance. Rene described that,

> You live day to day just to have—just to be able to have something out of your day to day. Because I don't have anything. I couldn't buy a cup of coffee if I wanted to. And that's sad. I'm 59 years old and I worked 20 years on the job. Ain't got nothing.

For women like Rene who received SSI or SSDI, federal guidelines determined their level of income assistance based on such factors as household size and history of Social Security taxes and payroll taxes paid. Although Rene worked 20 years as a certified nursing assistant, she was always considered as categorically low income. This meant that she had not paid enough in the way of social security taxes to receive much more than the minimum allotment. Most temporarily (un)stable women also had only themselves to report as household members and, because of this, received a monthly insurance stipend of only about $623. However, whether or not this income was sufficient to meet women's needs was shaped by a variety of life factors and circumstances often beyond the consideration of individual federal program employees or federal poverty guidelines. In some cases, women experiencing temporary (in)stability described how their legal histories affected eligibility claims for in-kind resources and, in turn, the efficacy of monthly disability payments.

For example, Treva found that her SSDI payments were not enough to meet all of her basic needs. Although technically proportioned to her life circumstances as a legally single woman with no children at home, Treva consistently ran out of food and had trouble paying her bills. As she explained why her income was insufficient, it became

clear that federal guidelines do not take into account factors complicating women's abilities to achieve daily life stability through income support programs.

> I was on methadone. I wrote a prescription for methadone and got caught. I did 123 days. And that disqualified me because it was considered a felony. So now I can't get no food stamps. That really stresses me out real bad. I paid for it. You know I'm on probation and I'm still paying. I called legal aid and they were supposed to send me some paperwork that might help, but I don't know what's up (Treva).

As Treva explained, her felony conviction for forging a medical prescription diqualified her from participation in the state food stamp program, despite that she was still eligible for federal disability payments. Treva's lack of food stamp allowance, however, affected her disability payments. Her grocery budget now necessarily cut into a monthly income that was already stretched thin by the demands of monthly rental and utilities payments. On just $623 per month, she paid $450 per month in rent, roughly $80 per month for utilities, $35 per month for a local telephone, and up to $12 per month for medication co-payments. This left Treva with about $50 per month for groceries and incidentals such as cleaning supplies and personal care items. She punctuated our discussion about her economic struggles with the realization that,

> "they [the state] just set you up to fail—or steal—when they cut you off like that. Their solution is for me to go to food pantries all week long. I don't think that's helping."

Unfortunately, a few weeks after our conversation, Treva "dropped out" of support services at Health Partnership. She remained out of contact with myself and program employees for most of the duration of this research. "Dropping out" or "laying low" was a common, though usually temporary, occurrence among women who felt that programmatic services could not address their issues in any significant way. The idea that program participation was not worth the effort it took to maintain enrollment was a response emergent from frustration and emotional fatigue.

> Muriel also discussed how the rules of different social support programs articulated with legal issues in ways that sometimes create contradictory or unintended affects among recipients.

> They'll put in jail for selling your food stamps. And then like if you can't make ends meet and you go down to see your caseworker, they just tell you to go get work. But you get work and then if you making a

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> dollar, they send you—you get a letter within 24 hours that they are
> raising your section 8. They want what you got. If you hide that dollar,
> they'll push you off [the enrollment roster]. They did that to me twice.

Social programs such as food stamps and Section 8 are technically intended by social service guidelines to operate together as a comprehensive approach to alleviating the affects of poverty. However, as Muriel described, enrollment in multiple services can actually complicate women's efforts for economic stability. Eligibility rules and stipulations concerning earned income and/or assets can end up negating the effects of technical entitlement. For example, many women reported that their food stamps were "cut" to $10 after they began receiving disability payments. As their income increased, their abilities to prove a need for nutritional assistance were diminished.

As described above, women in the temporarily (un)stable analytical category were often "one step away from eating it" (Lisa) (economic collapse) and/or one step away from thriving fairly comfortably in relative terms. Housing quality, material lack, insufficient income, and the eligibility demands of programmatic services can all be mediated by women's personal social support networks. As suggested in Chapter Four, temporarily (un)stable women were in various stages of substance abuse recovery and/or had achieved varying levels of disclosure to family and friends concerning their health. The emotional and social upheavals associated with disclosure and addiction recovery meant that women's personal social networks tended to consist of few operative members, if any at all. For temporarily (un)stable women, having few individuals to which to turn for support too often translated into coercive and/or abusive relationships. In contexts of social and economic upheaval, personal support networks present barriers to living well at the same time they might facilitate material comfort or advantage. Lisa's living conditions and small support network illuminate this predicament.

Lisa was one of the very few women in this research who lived in what she described as a comfortable home in a safe neighborhood. She, like all women described as temporarily (un)stable, utilized several social programs, including SSDI, food stamps, Medicaid, food pantries, and emergency assistance programs. According to Lisa, however, her greatest resource was her personal network (see also Stack 1974). Her personal network in some ways amplified the benefits of programmatic services

reception. At the same time, however, Lisa was left vulnerable to the demands and needs of the few network members who supported her efforts to live well.

During the time of this research, Lisa lived with her girlfriend of nine years along with her two teen-aged daughters. Lisa prided herself on being an "AIDS veteran" of sorts, having survived with HIV disease for more than a decade. She had long since survived being handed a "death sentence" by her doctor in the mid-nineties. She had also survived years of homelessness, crack addiction, the loss of her children to other family members, and periodic bouts of incarceration for theft and drug possession. What she feared and regretted the most, however, was tension between herself and her girlfriend.

Lisa often spoke of how much she cares for her partner. She would recount how they met, drifted apart, and came back together as proof that they were destined to share their lives. Lisa's feelings of love and admiration were sometimes complicated by her partner's mental health issues and their shared addiction to illicit drugs. The practical dimensions of maintaining a household under conditions of poverty, mental instability, and addiction were overwhelming at best. Yet, even should the worst of times arrive, Lisa felt that she could not just simply leave her partner. She emphasized that, without her partner's disability income, she would still be homeless and "running the streets." She also could not afford to care for her daughters and remain in their three bedroom rental house. Despite her sometimes rocky relationship with her partner, Lisa explained:

> I can't thank her enough. It's just what we have to do because that little $637 is not enough. I would have to live in a rooming house. The rent is 2-300 hundred dollars in the ghetto. Then you got to pay a light bill and how am I going to take my daughter somewhere in the ghetto? Oh a crack house, sure no problem. Then you got a water bill, a light bill, the sewer or whatever. And I just thank god for her because I wouldn't be able to do it. I would have to live in a rooming house. I had my experiences in a rooming house. And my babies were still with me and my daughter would come home from school in that environment. It's not fair to them.

The realization that Lisa could not afford on her own to raise her daughters in a safe environment led her to sometimes choose drug use over her long-term recovery goals. For example, one afternoon Lisa's daughters answered the door upon my arrival at their home. They asked me to talk with them alone outside because they were worried about their mom and they did not want her girlfriend to hear them. The girls explained that

Lisa had been trying to abstain from drug use. She had been smoking cigarettes and drinking beer, but had not smoked crack in close to three weeks. Lisa's partner, however, had begun trying to coerce Lisa into smoking crack when she was otherwise disinclined. Lisa's partner threatened to leave and withhold money from Lisa and the girls if Lisa did not oblige her girlfriend's requests for company while smoking crack. Lisa came outside and lamented the precarious position in which she found herself, noting however that, "…it could be worse if we were homeless. Then what would we do?"

In Lisa's case, the feeling of having to "put up with" her sometimes difficult relationship was put into sharp focus by the fact that she had recently inherited close to $35,000 from her mother. After taxes, Lisa had a little more than half of the money left. She knew, however, that $17,000 would not make a difference in her life for long— except that it could potentially disqualify her from receiving SSDI payments. She entrusted the money to her sister and periodically used it for cruise vacations with her daughters and small home improvements such as carpet and upholstery cleaning. Using the money to pay rent, utilities, or simply as a "nest egg" was viewed by Lisa as potentially damaging to her long-term stability because, per SSDI eligibility rules, the inheritance money would be an asset factored into her monthly income payments. Lisa feared that if Social Security found out about the money, they would ask her to pay back what she had collected in disability payments. Lisa felt that the money was most useful in smaller increments over the long-term future. Had she used the money to move into an apartment or house of her own, she would eventually face, once again, being unable to afford monthly bills. Lisa instead remained with her partner and focused her efforts on improving their existing living conditions. Thus like other temporarily (un)stable women, Lisa stayed put in the position of being "one step away" from thriving and "one step away from eating it."

The Material Circumstances of Vulnerable Women

27.5 percent of study participants are considered under the categorical label "vulnerable women." The women in this group were Health Partnership's most vulnerable HIV positive women. They struggled to obtain the documents necessary for

service use. It was for this reason, in part, that they struggled to meet basic survival needs such as shelter, food, and safety. The needs women in this group reported reflected their superficial attachment to programmatic services that were outside the purview of Ryan White legislation and funding. Lack of programmatic services support was, in turn, connected to vulnerable women's lack of sufficient income and their efforts to forge and utilize strong personal support networks.

Many of Midway's vulnerable HIV positive women had no consistent means of generating cash. 7 of 11 women in this group officially reported zero income. Only two women in this group qualified for and collected disability payments. Unofficially, women sold stolen items, participated in surveys and research studies, restored and sold items found in abandoned homes, and performed menial tasks as day laborers on construction sites. Women who did not collect SSI or SSDI payments and who also did not feel well enough to work lamented their fruitless efforts to enroll in income assistance programs.

Chantelle was one such woman who had no success with applying for disability insurance payments. Despite her diagnoses with HIV disease, schizophrenia, bipolar disorder, chronic fatigue syndrome, and carpal tunnel, Chantelle did not qualify for SSDI. As she described,

> I been trying for 5 years now. They did decline me 3 times, but we appealed it this time so we're still going for it. They say I'm not eligible for disability. I can work, I can do this, I can do that. Basically, they say I'm not sick enough. I would have to have 2 ailments. Well I got more than 2 ailments—they're just not the ailments they're looking for. Foodstamps are the only thing I have.

Chantelle described a common predicament among the most vulnerable women in this study. While she suffered from a variety of chronic and sometimes crippling health conditions, she did not meet disability criteria for HIV disease. She had been neither diagnosed with AIDS nor with opportunistic infections and thus did not qualify under federal guidelines for disability status. To complicate her financial situation, Chantelle's mental health issues, often exacerbated by drug and alcohol use, left her unable to function in the world of regular, consistent employment. She explained that when she was not "high" or drunk, she often felt too tired, "achey," or depressed to meet the demands of a job. The intensity of her drug use made it altogether unlikely that she

would be able to keep up with the schedule and physical demands of regular employment. Chronic fatigue and carpal tunnel syndrome further disqualified her from the informal, day labor job market because she could not physically cope with the demands associated with working at construction sites and with cleaning services. As a result Chantelle, like many women in similar circumstances, survived with no means of regular income.

Jamie also survived without a regular means of income generation. For several months, Jamie had been experiencing chronic and debilitating diarrhea that made leaving the house, let alone formal employment, nearly impossible. Her current financial predicament was intractably tethered to the guidelines used to determine eligibility for income assistance programs.

After her diagnosis in 2000, Jamie felt that her work as kitchen staff was inappropriate, given her HIV positive status. She feared being on the job market in the context of a career shift and began stealing from the restaurant cash register just before she quit. Stealing was meant to provide a cushion for her while she looked for other training and employment. However, her decision to steal from her place of employment ultimately rendered her as unemployable in the local retail job market. After being caught stealing, Jamie had no references or professional network through which to secure new work.

Jamie has had no means of formal income generation since 2000. She lost her children to social services for charges of neglect that stemmed from her inability to afford basic necessities such as food and electricity. For a few years, Jamie relied upon selling drugs and "boosting[xviii]" as a strategy for obtaining money. Jamie began trying to "pull it together" in 2008. Her first step was to apply for disability income so that she could have a stable environment in which to recover her health and custody of her children. She found, however, that over the years she has accumulated an arrest record, a powerful addiction to crack, and several case notes in her social services file that indicated how her addiction translated into a history of poor service outcomes. These conditions affected her disability payments and her efforts to secure work. As she explained,

> I mean my disability is like only $473 when I get it. They take some out
> for old fines, or something. I don't think that's even the minimum and
> they won't give it to me at all without a payee. I mean these are people

who need these things for their lives. Like, for me, it's hard to get a job because I have a record that includes theft. Even though I dealt with it, it's still on my record so when they pull it up, all they can see is what I used to be. But that's not who I am trying to be now.

Jamie felt an earnest desire to move beyond the sometimes self-defeating survival strategies she had employed in the past. She was willing to adhere to programmatic service rules as a means of demonstrating her commitment to changing her life. This long-term commitment was sometimes difficult to maintain in the face of short-term needs. For example, in order to receive SSDI, Jamie is now legally required to have a payee who is neither her children nor her partner. While she looked for an appropriate payee whom she could trust, Jamie struggled to keep food in the house, purchase medications, and keep her household utilities running. These struggles were complicated by the fact that she lived in her partner's home with no legal rights to occupation. Jamie often discussed how her partner would never "put her out of the house," but she sometimes wondered aloud what she would do if the unthinkable happened. Her status as technically homeless in the context of earning zero income remained a significant source of her worries.

As discussed in Chapter four, all of the vulnerable women in this study would be considered by social service officials as technically or actually homeless. Technical homelessness includes for situations, like Jamie's, wherein women live with friends, partners, or relatives, but do not have the legal protections of a leasing agreement or other such contracts. Informal living arrangements with friends or family, even when intended as long-term solutions, did not tend to afford women material stability, privacy, or "piece of mind" (Rosalind).

Chantelle told me during an interview that she needed nothing other than the clothes on her back, food stamps, and a place to wash up every day.   Having endured homelessness for eleven years, Chantelle employed strategies for daily survival that were sophisticated and hard-learned, if flawed. She was proud in a certain way of her experiences as homeless because they showed her that she could survive even the harshest of conditions. Principal among her strategies for survival was maintaining an intentional lack of material goods. As she described,

The more shit you carry around, the more people will fuck with you

for that shit. The more shit you carry around, you are a bigger mess
when you want to stay with someone at their house."

As a woman who knows "the hustle" that life on the streets can entail, Chantelle helped to ensure her own safety by carrying nothing more than her clothing, food stamps, and a picture of her deceased son. In the past she had made the mistake of carrying medications on her person. She was "jumped" by two men who mistook her mental health medications for pain pills. At the time of this research she took her medication doses at the health department when she could. Chantelle forwent other material items because of the trouble their potential value might cause among her peers. Until some very basic circumstances changed, Chantelle wanted only to eat well, stay warm, and avoid the physical danger that homelessness sometimes involves. When asked what her needs were at the time, Chantelle responded that she needed identification cards and a lawyer.

Chantelle's identification had been verified through her various stays at in-patient mental health facilities, prison, more than twenty stints in the local jail, and more than occasional visits to local emergency rooms. Yet, social services could not assist her beyond the provision of food stamps. Chantelle needed to prove who she was to the state of North Carolina. Proof of identity protocol required her to obtain her birth certificate from the state of New York. She could not find a program that offered cash assistance for buying her birth certificate without proper ID. With no ID, she had no bank account, means for employment, or money of her own to speak of. Enrolling for housing subsidies, public housing programs, and cash assistance programs was virtually impossible without obtaining a state-issued ID card. Chantelle had lived with this conundrum for several months before scraping together the $15 she needed to purchase her birth certificate.

Once she had her ID, Chantelle needed legal assistance for settling her criminal record before housing authority officials could process her application. Chantelle had never fully settled formal charges brought against her for arson and check fraud. While she "did time" in prison and jail for these charges, fees, fines, and paperwork remained stacked against her. In the meantime, she alternated between staying with friends,

checking into the local homeless shelter, or sleeping outside with a group of people in whom she found safety.

Like many women who found themselves without a consistent place to stay, food stamps—and more of them—were among vulnerable women's most immediate needs. Food stamps could be traded for money, drugs, and/or shelter. Like many valuable resources, food stamps were not easy to obtain for women who had few documented financial burdens such as bills to prove their need. Technically homeless women, in particular, fought hard for access to food stamps. The problem, according to women, was that social service guidelines seem to suggest that having neither a lease nor utilities bills in one's name indicated a lack of need for assistance. Women who could not prove that their financial needs exceeded their monthly incomes were denied food stamps or given the minimum allotment of ten dollars per month. As Tasha explained,

> See like right now, well see I just got out of jail. I'm not trying to brag about it or nothing, but I did 98 days and so I just got out of jail like right before Christmas. I'm staying with a friend. See I don't really have a apartment or house or anything like that. I'm staying with friend and so they only give me like $10 in food stamps because I don't have any bills to show that I need them.

Tasha's disability payments had been suspended and she found that technical homelessness kept her from being able to claim full food stamp benefits. She waited for her income payments to resume, "making do" by relying on friends and food pantries. Other women had informal agreements with family members and children in the care of other relatives that allowed them to claim food stamps on their behalf. Whatever the means by which they were obtained, the importance of food stamps for women's strategies to secure some form of material security cannot be overestimated in this context.

Other informal arrangements called for women to shoulder the entire burden of obtaining food for a household. For example, Donna's roommate paid all of the bills, including rent, while she was responsible for providing meals and snacks for the two of them. The original agreement between Donna and her roommate was for Donna to pay connection fees and utilities bills for the two bedroom duplex. However, Donna lost her job as a CNA and could no longer afford to uphold the original deal. A year after losing her job, Donna and her roommate still did not have hot water or heat. She simply could

not pay the bills. She is not a lessee in the housing contract, but the utilities were in Donna's name. Having the bills in her name enabled her to qualify for full food stamp benefits. To compensate for her inability to pay utility bills, Donna began sharing her food stamps with her roommate.

Donna could not stretch $125 per month in food stamps far enough to feed two people. She found herself regularly seeking assistance from area food pantries and churches. Some months she was "frantic" trying to provide enough food for herself and her roommate. When asked what would happen to her living arrangements should she not provide food for her roommate, Donna explained that the deal was simple. Her efforts to feed two with zero income and $125 in food stamps were a necessity if she wanted to remain indoors for the winter.

> It all boils down to me having a place to stay. Me having a roof over my head, something to eat, and trying to make ends meet. Especially because it's cold outside and we getting ready to have some ice and snow. I dealt with being homeless already so I just do whatever so I don't go back out there (Donna).

Although food stamps are technically intended to provide nutritional assistance to the poor and working poor, they do much more than that for Midway's most vulnerable women. As Donna alludes, they are a "bargaining chip" for women who have no other means of paying rent or contributing financially to household maintenance. Without food stamps, women had little autonomy when it came to meal preparation or protection against being asked to leave someone's home. Food stamps could be traded for a modicum of material comfort. Clearly, however, food stamps could not alleviate the potential social vulnerabilities women faced as HIV positive and technically or actually homeless.

Given the intense lack of basic necessities such as shelter and income, Midway's vulnerable women were particularly reliant upon the support of personal social networks. In contrast to the experiences of temporarily (un)stable women, vulnerable women participated in networks that were frequently long established and largely intact. Vulnerable women described that many of their networks were forged and maintained through illicit drug use and associated activities. These networks nonetheless functioned as a sort of safety net for women who had few other places or people to which to turn.

Tasha represents one such woman for whom her support was mostly garnered through what she described as "using friends." Tasha had been released from jail in December 2007 following an arrest for arson. After years of what Tasha described as emotional abuse and neglect by parents who favored her siblings, she poured gasoline on her parents' living room floor, lit a match, and left the property. The family members inside the house at the time escaped physically unharmed. They pressed charges, however, and Tasha was promptly arrested. After a court conviction, she was not legally allowed to visit family or return to her family's home. Tasha had nowhere to turn after being released from jail but to the friends with whom she did drugs.

Tasha's friends allowed her to stay with them while she reinstated her disability payments and completed the probationary period following incarceration. The conditions under which she stayed were less than desirable. Her "roommate" frequently made unwanted sexual advances. When Tasha refused his advances, he would lock her out of the house or refuse to allow her to use the bathroom indoors. As she explained the situation,

> Half the time he was making me piss outside in the trash can—it was
> crazy. And then you know I was kicking out—because wherever I go,
> of course you know I'm going to pay my way. I ain't sleeping with
> nobody just because I need a favor. Yeah you letting me stay, but I
> will pay you something. It got to be where I had no choice but to leave.

Tasha did in fact leave that situation. She considered herself as lucky because she had another "party friend" to which she could turn for support. She next turned to an old friend with whom she had "run the scene." He was also HIV positive and so shared Tasha's concern for privacy. In addition, this friend was gay and uninterested in coercing Tasha to perform sexual favors in lieu of financial contributions to the household. Together they tried to abstain from using drugs and alcohol, but found sobriety difficult to achieve. After a few months, Tasha's friend was gravely ill and she felt it was time to leave again. Tasha's disability payments had been reinstated by this time. She was receiving close to $900 per month in disability payments. She was still unable to secure an apartment of her own, however. Her criminal history, inclusive of arson charges, rendered her as a leasing risk that landlords were not willing to take. This time she moved in with another friend until the absentee landlord evicted them both so that he

could move to Midway and live in the property himself. Tasha then began alternating between staying at the local shelter and renting hotel rooms. When I exited the field two months later, Tasha was still surviving in this housing pattern, although she was talking with another homeless woman, whom she had known from years before, about moving in together[xix].

As described above, the conditions of technical and actual homelessness leave women disproportionately dependent upon personal social networks for daily survival. Vulnerable women's basic needs seemed most often met through informal arrangements such as living with friends or family and trading food stamps for financial contributions to the household. The demands placed on women in this context were emotionally taxing. Much like the social network experiences reported by temporarily (un)stable women, vulnerable women often found themselves in coercive or abusive living arrangements. Although their addiction issues and histories of incarceration were comparable to those of temporarily (un)stable women, their lack of attachment to family and the conditions of homelessness rendered them as differently vulnerable to material want. Vulnerable women, however, did have more personal social network members to whom they could turn for support in times of desperation. In addition, a lack of material possessions and financial responsibilities facilitated moving on from one spot to the next rather rapidly. Vulnerable women's lack of attachment to social programs such as Section 8, public housing, and disability income afforded them a bittersweet freedom from eligibility criteria and reporting requirements pertaining to changes in residence and household makeup. The emotional toll imparted through the challenging conditions of financial instability and social vulnerability, however, should not be underestimated. Indeed the vulnerable women in this study emphasized the misery they felt in connection to their living conditions and the burdens born for the creation and maintenance of dense personal social networks.

I met Rosalind in the lobby of Health Partnership. The day I met her, she cried to me that she lived "the life of a hermit" because she feared others would learn of her HIV positive status. Rosalind lived with her mother and son in a neighborhood controlled by one of the local gangs. Her fear of violence and violent crime exacerbated the stress she often felt in relation to her poverty and life with HIV disease. Having zero income and

only food stamps to which she could turn for support, Rosalind relied on neighbors, friends, and family for financial assistance. Rosalind suffered from arthritis in her spine. On many mornings, she could not get out of bed without assistance. The pain she felt was constant and exhausting. Neither the arthritis nor her HIV status qualified her for disability income. As a former medical records clerk at a local hospital, Rosalind knew too well how employees sometimes discussed the health records and medical charts they came across. Rosalind used an alias at the physician's office and avoided any discussions of health with those to whom she turned for support. Her mother and son did not know her status. Rosalind prayed that she would not unintentionally reveal her status as HIV positive to friends by "acting funny" when the virus was brought up in casual conversation. She described her fear of being found out as emerging from self-preservation and the fear of being abandoned. As she described,

> To avoid it [social contact] means not putting yourself in the position to meet that person who needs to know. People in the world are very ignorant. They do not know that there is life after the virus. I just don't know that it's my job to teach people that at my expense. …That expense is feeling like you're less than. Being treated like you're less than because you got it. Being cut off.

Rosalind's decision not to disclose her HIV positive status was a means of self-protection. Emotionally, non-disclosure shielded her from negative reactions and judgment. Materially, non-disclosure helped to ensure that personal social network members would not abandon her in times of need.

Over the course of this research, Rosalind grew weary of keeping secrets. She avoided going to Health Partnership during its peak hours lest she see an acquaintance who might gossip. She began calling program employees from the parking lot and asking who was inside. During informal conversations at the organization, she grew increasingly agitated. Rosalind constantly watched the front door for prospective trouble and described her fears of seeing any fellow Health Partnership participants at the grocery store or in her neighborhood. Paranoia began to take over, and Rosalind felt that she had to disclose her status to a family member to alleviate the burden. She chose her brother and his initial response was supportive and kind. A few months later during an argument, Rosalind's brother told her that he was glad that she was dying of HIV. Rosalind felt betrayed, distraught, and emotionally wounded by his insensitive remarks.

As I exited the field, Rosalind was seeking financial assistance for mental health services so that she could check into an in-patient psychiatric facility. As in Rosalind's case, keeping one's HIV positive status a secret was a burden shouldered by many of the most vulnerable women in this study. In the end, shouldering this burden provided one strategy for maintaining access to basic needs such as shelter, food, and support.

The Material Circumstances of Stable Women

The stable women in this study experienced material conditions that were less often stressful than those experienced by their temporarily (un)stable and vulnerable counterparts. Stable women tended to most often struggle with satisfying material needs that service providers often viewed as being of only secondary importance in relation to housing, hunger, and health insurance. For some stable women, "primary needs" such as housing and income were long ago met through enrollment in social programs. For other stable women, "primary needs" were met through income generated through employment, pensions, and inheritance. That stable women's primary needs were satisfied through a combination of programmatic services and employment is significant. The types of needs that arise once primary needs are met are also significant for experiences of health. I thus do not want to suggest that stable women's material needs are any less important than the needs reported by vulnerable and momentarily (un)stable women. Rather, I suggest that stable women's material needs represent another interlocking set of circumstances along a continuum of HIV health needs and survival experiences.

In terms of monthly income, the stable women in this study tended to generate money through a variety of resources including spousal support, SSI, SSDI, pensions, part-time or full-time work, and inheritance. Using a combination of income assistance programs and economic resources meant that stable women tended to have greater incomes than momentarily (un)stable women and vulnerable women. On average, stable women tended to generate about thirty percent more money each month than their momentarily (un)stable counterparts. Yet, despite that stable women had multiple sources of bringing in money, they remained categorically low-income. Ashley, for

example, earned approximately $1,400 per month through SSI and employment as a CNA. Ashley reported feeling fairly financially secure even though she was technically a low-income woman. She described that,

> My rent is only $300 because I have section 8. I pay water, sewage,
> and trash. I have not a lot left after I pay my bills, but then again I
> have more bills because I can afford more. I got life insurance. I
> got a car and car insurance. I got renter's insurance in case
> something happen to my apartment like a storm or anything. I don't
> really have anything left, but I do right by myself so I can basically
> afford some of what I want [rather than need] like my car.

Thus despite that Ashley did not have a lot of money left after paying each month's bills, she felt overall fairly comfortable living on the income she earned. Ashley discussed her experiences as a woman who was categorically-low income. She was acutely aware that her financial situation was less stressful than the situations of many women she knew through Health Partnership. Her frequent iterations that she was "doing right by herself" pointed to the pride she felt at being able to pay her own bills with relatively few financial emergencies. This feeling of being financially viable, despite one's low-income status, was a general trend among this particular group of women.

DeeDee also felt financially viable despite her low-income status. DeeDee received $1167 per month in pension for her previous career in the US military. She also earned approximately $700 per month doing part-time work through a local temporary employment agency. DeeDee constantly searched for full-time employment that paid more than minimum wage. As a high school graduate with some college experience and a former career in the US military, DeeDee expected to earn no less than ten dollars an hour. Though she was unable to find secure work during the study period, she managed to save close to five hundred dollars each month. DeeDee generated enough income that she neither qualified for nor wanted disability insurance payments.

Charlotte, on the other hand, qualified for disability insurance based on health factors other than HIV. Her former career as a factory worker was cut short by carpal tunnel syndrome and multiple injuries to various upper body muscles. Charlotte hit "rock bottom" in the early 1990s with an addiction to cocaine and a physical inability to work. When she lost her home, Charlotte realized that she needed support. A friend explained to her that her injuries might render her as eligible to receive disability benefits. In 1996,

Charlotte's application for SSDI was finally approved. At the time of this research, she

received approximately $950 per month. In Charlotte's case, financial viability would be

an impossibility without participation in other social programs such HOPWA housing,

food stamps, and emergency assistance programs. She explained during an interview that

the resources in Midway enabled her to make ends meet:

> There are so many places that it will like overwhelm. It's so amazing.
> But that individual will have to go out and get it. It's not gonna just
> happen. Which I have seen places where they'll bring your food.
> American Red Cross, they would come pick you up and take you to
> your doctor's appointment. So the resources are great in this area, the
> resources are great. Whether you dealing with medical bills or need
> some rent paid or a light bill paid, it is really here. If you go after it,
> you can have what you need.

Charlotte's awareness and use of area programs and resources for low-income

individuals enabled her to live in relative comfort with minimal financial emergencies.

Joan likewise discussed needing the extra support of social programs designed to provide

subsidized rent, utilities, and nutritional support. She and her husband together received

$950 per month in SSDI and SSI payments. Joan was diagnosed as HIV positive as a

teenager. Early on, she experienced a serious bout of ill-health and needed to access

income assistance programs. Because her abbreviated work history means that she had

not paid much in the way of social security taxes, Joan receives only $327 per month.

Although the combined $950 per month is well below the federal poverty line, their

participation in the Section 8 housing program capped their monthly rental payments at

$120. Joan's utilities bills and lights are also subsidized through a social services energy

assistance program available to low-income individuals. They pay portion of each

month's bills not to exceed thirty percent of the total charges.

Grace, too, was a participant in multiple social programs that together kept her

financially stable and somewhat materially comfortable. Grace was a former public

school teacher who could no longer work. Over the course of two weeks, Grace suffered

from a serious stroke that left her partially paralyzed with mild mental impairment. She

learned that she was HIV positive. And, she found out that her husband had been

cheating on her. To say that Grace was devastated by this overwhelming news is an

understatement. Grace cried frequently throughout formal interviews, but insisted that others should know her story because it is ultimately one of triumph and strength.

Upon being released from the hospital, Grace enrolled in the SSI program, food stamps, stroke survivor support groups, and her case manager set her up with a payee. In addition, Grace's teaching career provided her with a small pension for her service. Though she was unsure exactly how much she collected each month from SSI and her pension, she knew she had the basic resources that she needed to make ends meet every month. Grace's payee, a social worker who was employed by the hospital, took care of her bills each month. She qualified for the hospital payee program specifically because of her stroke and the brain injury from which she suffered as a result. Her payee, "Mr. Eric," paid $630 per month in rent and approximately $200 per month for cable, telephone services, and electricity. Mr. Eric reserved one hundred dollars per month for Grace to spend as she felt was necessary. Grace most often used this money to supplement the $179 per month she received in food stamps and to purchase cleaning products and personal care items. Grace often requested more spending money, but Mr. Eric explained to her that her budget was already stretched too thin. In fact, Mr. Eric sometimes requested emergency assistance from hospital and social service programs on Grace's behalf. No matter what her financial situation, Mr. Eric made sure that she had at least that little bit of cash on hand. Grace knew that she was more financially viable than many women living on public assistance, but lamented her lack of disposable income:

> I'm paying $630 a month in rent. And then my light bill and my phone, and my cable. I have a life insurance policy. Sometimes the light bill is being paid for by Mr. Eric—not even my money. And he pays my cable when I can't too. And I get my food stamps. So then he don't have nothing to give for me to buy my makeup or buy my shower gel or stuff that women needs cosmetics and stuff. I don't have money for that. It's just hard because those are the things that make you feel pretty like when you see other people when you go out. I used to be a school teacher and I could buy the things I needed. Now I can't even wear makeup like a normal woman does (Grace).

Despite that Grace can meet her basic needs for shelter and food, she still has material wants and needs. In particular, Grace wanted for material items such as cosmetics and shower gels that she felt were conducive to mental and social health. Indeed, many stable

women talked about the needs they feel as consumers. Updated clothing, salon visits, designer glasses, cosmetic dentistry, and gym memberships were a few of the material needs that stable women reported in relation to their efforts to feel good about themselves. As Charlotte described,

> I can't be sitting here with a jacked up mouth [crooked teeth]. My teeth
> are very important to me. People see your teeth and when they look
> bad, they assume bad. When you look at your own teeth and they look
> bad, you feel bad about that first thing you present to the world—your face.

For Charlotte, dentistry was not just about oral health. It was a way to maintain a positive self-image and to project that image to others. Charlotte had slowly taken on the financial burden of braces for her teeth. Straightening her teeth, though technically not considered a health need by Medicaid and Medicare programs, was important to Charlotte for emotional and social reasons. Had she enjoyed greater income or private insurance, dentistry bills might not have been such a financial burden. Similarly, Tamara discussed how outings such as shopping at the mall, eating in restaurants, and going to the occasional movie can help to alleviate her depression because they were activities that she enjoyed prior to diagnosis with HIV disease.

> These are things that I do for fun. You have to just continue doing what you
> used to do. They're things that I would do if I were living with this [HIV
> disease] or not. It's not as easy now that I don't work anymore, but my
> husband takes care of us. Doing these things is part of my normal life. We
> have fun.

Tamara explained that participation in consumer culture via shopping and seeing movies helped her to feel like she's living the life she would without HIV disease. Like Charlotte and Grace, Tamara indicated that once women are "freed" from concentrating on how they will meet basic needs such as food and shelter, they can begin addressing their social and emotional needs. Working towards living "life as normal" was an important part of women's emotional strategies for coping with loss of income, health crises, and the emotional burdens that often accompanied an HIV positive diagnosis.

As described above, stable women's incomes, though well below the poverty line, tended to be experienced as viable with respect to basic needs. Income viability, in turn, translated into housing stability. Stable women tended to enjoy better housing circumstances and prospects than their temporarily (un)stable and most vulnerable

counterparts. Joan and her husband, for example, rented a small home in a middle class subdivision on the outskirts of Midway.

The outside of Joan's home was welcoming and lush. Large trees, a green lawn, and small beds filled with flowers and vegetables greeted visitors. Joan was happy to report that, although their home was small and old, it was pest free and in a safe neighborhood. All appliances worked and Joan had even recently requested and received a new refrigerator from her landlord. As we sat in her living room well furnished with hand-me-downs, donated items, and "large ticket" items such as a big screen television, Joan described why she enjoyed her house.

> I lived in this house five years. I love this house. The rooms are nice
> and big. We have our own yard, a driveway—we don't have to fight
> for parking spaces. It's lovely. We have our own backyard. It's a old
> house, but it's a good house. It's in a good neighborhood, not a bad
> neighborhood. We don't really have to stress about anything there.

Joan discussed that the house she rented with her husband was well-suited to their efforts to avoid stress. The house was large enough to accommodate their needs, including an outdoor patio that they dedicated to meditation and relaxation therapies. Joan lived in the house for five years and did not imagine that they would have any need to move in the foreseeable future.

Stacey also lived in a home where she felt very comfortable and safe. Three years ago, Stacey struggled to pay rent for a sub-standard apartment. At the time, she was in active addiction and unable to afford a better place to live. Now, however, she worked and lived in a recovery house for women. Stacey was herself well on her way to achieving long-term sobriety and now had employment as a "house leader." She worked for room and board and so did not have to pay rent. Stacey loved that the house was clean, quiet, and on the outskirts of town. As she described,

> I really like I where I live now. I don't really have to worry about any-
> thing house-wise because it's all taken care of. It's clean and the rooms
> are nice. We make meals that are good for us. There's a backyard where
> you can go and just be quiet and listen to the birds. I would stay there for as
> long as they'll [administrative staff] let me.

Stacey described how "peaceful" and "comfortable" her living arrangements were. She appreciated the cleanliness and spaciousness of the house. She had no plans of moving

anytime soon. Most of the most stable women in this study reported that they enjoyed living in their homes, apartments, and neighborhoods. Two women, however, had aspirations and plans for home ownership.

Charlotte and DeeDee both had professional work experience, some college education, and plans to move into lucrative careers. Both women were planning to find full-time, well-paying employment. As mentioned at the beginning of this chapter, DeeDee received a pension for her military service and worked regularly through a temporary employment agency most often as clerical support. She was saving approximately $300 per month for a down payment on a home. Despite that her military pension plan included access to a program for home ownership based on providing low-interest home loans, DeeDee wanted to take her time and save as much money as possible. She was able to save her money because she lived with her mother throughout the course of this research. She performed care work in lieu of paying bills and rent. Her mother had recently undergone surgery and needed help performing menial tasks such as cooking, cleaning, and doing laundry.

Charlotte, on the other hand, lived in an apartment that was subsidized through the HOPWA program. She described how she "loved" her apartment because it was in a beautiful neighborhood near a college campus. Neighboring yards were landscaped, the homes were historic, and her apartment blended in with the rest of the homes in the area. When asked if her rent was expensive Charlotte responded,

> No my rent is based on my income. I pay about a hundred dollars a month. I live in one of the HOPWA housing. Thank god for places that provide residence for people that are HIV positive. It's just set up over there so that we can blend into the community. As far as people are concerned over there, it's another big pretty house.

Charlotte appreciated that she had a subsidized apartment and lived in a "beautified neighborhood." She often said that the housing placement to which she was assigned was "[her] wildest dreams" come true. Charlotte also often spoke of wanting to own one of the homes in the neighborhood. She conceded that those particular homes were more than likely prohibitively expensive. Still, she began to take the steps necessary for future home ownership. In 2006, Charlotte began saving for a home down payment. She worked with a local program for low and medium income individuals who want to be

home owners. The program was designed to match the down payments of prospective buyers. Charlotte saved nearly $1800 (the program matching maximum for low-income families) over two years and was ready to explore the homes she would be able to afford with the matching payment. She found, however, that the homes for which she qualified were less than suitable.

> I just refuse to live in a bad drug infested area. You know if the house is there, I will still take it because I'm living in my house, I'm not living on the street. But if I have a choice in the matter, and I do have a choice, I'm not going to accept a house that it's in a bad infested drug area. Because I have grandchildren. And their health, and safety, and well-being means everything to me as well as my own. So I have choices today.

The choices of which Charlotte spoke included her decision to seek well paying employment. She worked throughout the year towards obtaining her chemical dependency counseling license. This career move would mean that Charlotte would qualify for a more expensive home because she could afford a more expensive mortgage. She knew that a boost in her monthly income would also mean that she would have to save more money to qualify for a medium income matching grant. She did not imagine, however, that this would be a problem given that she had managed to save nearly $1800 with the help of programmatic services support and disability insurance payments.

In addition to using various programmatic services in their efforts to maintain daily life and financial stability, Midway's most stable women had undergone some dramatic changes to their social networks. In contrast to vulnerable women who tried (sometimes to the detriment of their physical safety) to maintain as many operative network members as possible, stable women honed their personal support networks to include service professionals and financially and emotionally stable friends. Their abilities to maintain friendships with service professionals and similarly positioned individuals were enabled by stable women's abilities to participate in activities such as occasionally dining out and going to the movies.

Stable women also honed their personal networks by disconnecting from members who used drugs or who were insensitive about HIV disease. Women such as Joan and Tamara who had never dealt with chemical dependency issues did not necessarily go through the process of "shrinking" their networks. However, women who

had traveled the roads of recovery did go through the process of "letting go" of old social patterns and networks. They could afford to do so because they had a kind of financial and social security that vulnerable women did not. Any "associates," friends, and acquaintances who might have been part of women's past lives as drug users, drinkers, or dangers to themselves could be and, for all practical purposes, were left behind. DeeDee explained that:

> I don't have a lot of friends. Friends get you in trouble. You know what my grand mama always told me, if you buy a person a plant. If that plant lives, that's a true friend. If it dies, she said "Run like hell. They mean you no good." And a lot of friends is like that when you out there using drugs.

DeeDee's remarks that friends get you in trouble come from hard learned experience during the times when she was in active drug addiction. Her lack of friends in the present context is a strategy for avoiding the trouble that can accompany drug use and addiction. Charlotte similarly explained her lack of friends during the time of this research:

> It depend on the person if you're not on real good solid ground, it is in your best interest to leave the idea of any friends behind. Because drug addiction is very powerful and people will get you back to using and involved in a cycle quicker than you can clean. So like I don't try to go out there and convert nobody or try to persuade them to stop using. You don't even hang with them anymore.

Like other women who had achieved long-term recovery, Charlotte and DeeDee chose to leave old friends behind to prevent the possibility of future drug use relapse. Other women also disconnected from friends when they felt they couldn't trust them to keep their HIV status a secret. As Danielle described,

> I really only have like one or two real friends now. You can't tell everybody What you got. …So if it's somebody that I like, but I don't think I can tell Them about the HIV, then I just stay on the surface with them. You know, "hi, how are you doing?"

Danielle explained that a friend should be able to know one's HIV positive status. In the absence of confidence about a person's ability to take this information in stride, stable women tended not to pursue the friendship beyond "surface-level" pleasantries. This situation meant that stable women, compared to other women in this study, relied most heavily upon programmatic services to meet their needs. This reliance, as I explore in depth in following chapter, included for social, emotional, and financial needs.

Analytically "unpacking" the categorical label "low income" required attention to the subtle details of women's lives and personal histories often left unaddressed by social service guidelines and service protocols. The insights provided by women about their own lives, social positions, and living conditions rendered clearer the differences among women so often assumed to share the bottom rung of the social ladder. These differences were manifest in Midway, at least in part, as variability in living conditions, material wants and needs, and sources of income and support. It was in this context of variability that locally-implemented federally funded AIDS care programs functioned to mediate Black women's strategies for health and survival with HIV disease.

CHAPTER SIX:
INSTITUTIONAL NETWORK STRENGTH AS A MECHANISM OF HEALTH

> You have to think about how to improve your circle. Like I don't really
> know what I know about how to live with HIV. I think I know a lot, but
> you have to keep going to know all the stuff you can so you know who
> you need in your circle so that you can do what you need for yourself
> (Stacey).

Social networks provide an important means of survival for women who are living with HIV disease. As described in the previous chapter, women's living conditions and health needs are interconnected with the financial support they are able to garner through social program enrollment, income, interdependent relationships, retirement pensions, and gifts. Income assistance programs, rent subsidy programs, food stamps, and other such government-sponsored services provide the means for many women to achieve at least a modicum of the daily life stability needed for health. In the context of differential access to and utilization of social services programs, Midway's Ryan White system of care functioned as a safety net and a source of health-related resources. However, women experienced participation in Ryan White health care programs differently in relation to the socioeconomic contexts of their lives and their abilities to make use of particular forms of social capital.

Social capital, as described by Bourdieu (1986), refers to the total (actual and potential) resources produced and obtained through a "durable network" of more or less institutionalized relationships. Social capital is thus derived through beneficial social relations that are maintained over time. The amount of social capital that an individual has for her use depends upon the size of her social network and the amount of social capital possessed by those to whom she is connected. In other words, social capital represents the benefits of belonging to a particular group. The "benefits" of social capital are realized as the ability to appropriate social energy in the form of labor. This "labor" is here envisioned in relation to client/provider relationships in the system of HIV care.

I use Bourdieu's concept of social capital to emphasize that social relationships within the Ryan White system of care structure women's abilities to advance their own social and economic interests. Bourdieu's focus on the benefits of social relationships

necessarily implies that group membership and/or social networks are cultivated resources used within the milieu of particular social struggles. In one sense, I make use of the concept of social capital as a way to understand and explain women's motivations and strategies for engaging with the sometimes daunting physical and emotional work associated with programmatic service enrollment and behavioral modification techniques. In another sense, I use social capital as a means of maintaining focus on the reality that study participants made choices in using social relationships. In other words, women strategically positioned themselves in relation to perceived and actual benefits of membership within the local HIV positive service community.

It should be noted, however, that Bourdieu's social capital concept does not maintain focus on processes of relationship building and the maintenance required to sustain the benefits of group membership. His conception suggests that social capital is a durable resource because it has been more or less institutionalized (Bourdieu 1986:248). In other words, social capital represents a benefit to be acquired and possessed. It is in this way that the concept of social capital fails to account for the fluidity of the processes through which social relationships are made meaningful as potential sources of advancement. The concept is unable to account for the ways in which women's struggles are shaped by the changing contexts of federal legislation and programmatic services. For this reason, I must concede that "social capital" provides only a theoretical "short-hand" for much more fluid social processes.

Nevertheless, in this chapter I illuminate how women use particular forms of social capital in the "social field" of HIV/AIDS care and support services as a strategy for survival and, for some, socioeconomic advancement. I include women's experiences with Medicaid case management as an important part of this discussion. Although Medicaid case management is not a Ryan White-funded program, it is an integral component of HIV/AIDS care and, for many, a point of access into Ryan White programs. For other women, case management presents another set of obstacles to realizing the right to quality care. I thus draw from women's experiences with Ryan White services and fee-for-service case management programs as a means of exploring the dynamic interplay among the structure of programmatic services, strategies for health, and service outcomes.

Pedagogical Contexts and the Means for Social Network Surrogacy

Using the Ryan White care system as a surrogate social network did not happen in a vacuum. Rather, there were various contexts that articulated with women's living conditions and health-related needs in ways that enabled them to conceptualize and utilize (or at least try) the system in this way. Service provider efforts to instruct HIV positive individuals in conformance with the individualizing logic of biomedicine (Lupton 2003) were at the core of this dynamic. To date, biomedical intervention is the only federally-funded means of treating HIV disease.

Educational forums and conferences organized by local care providers and HIV-related institutions provided two of the more formal venues where women learned biomedical perspectives on life with the virus. For example, Midway's annual "treatment update" conference focused on facilitating dialogue between medical practitioners and their HIV positive patients. The forum was specifically designed as a means through which doctors and clinical trials representatives could communicate advances in treatment and care. The local Community Advisory Board (CAB)[xx] organized and facilitated the meeting. The year that I attended, clinical trials representatives emphasized the relatively quick and impressive advances made in AIDS treatment. Since the days of AZT therapy, 28 new drugs have been developed that provide a means for managing HIV disease before the onset of AIDS. In addition, viral load, medication resistance testing, and CD4 cell counts all provide relatively new means of tracking patient responses to HIV infection and progress with therapy. The clinical trials community was happy to announce that over the past year, three new drugs were approved for the treatment of HIV infection[xxi].

The annual educational forum also served as a platform for the dissemination of particular ideas concerning survival with HIV disease. It seemed as though the medical community in general interpreted the TMA as a concrete step towards ensuring equal access medical technologies for low-income and otherwise disenfranchised individuals. While the TMA might legislate access to care, utilization was regarded as one's personal

responsibility. Such an understanding was evident in the topical theme of guest speakers brought in to complement the clinical trials reporting.

For example, a "lay" guest speaker focused on communicating a message of adherence. He explained that statistically, as a gay white man who was diagnosed in 1984, he should not be alive. His success as a twenty four year survivor, he explained, was due to his diligent efforts to build a life around the notion of adherence. The speaker related his long-term survival to such subjects such as returning to work, volunteerism in the HIV positive community, and one's responsibility to build a support team. Physicians, case managers, pharmacists, peers, and family/friends should all be rallied in support of one's health care and maintenance. This meant building positive, working relationships based on the needs and accomplishments of the "patient." The speaker further urged HIV positive individuals to keep track of their viral loads, CD4 cell counts, and medication side-effects. These efforts, he argued, were the keys to thriving despite an HIV positive diagnosis. This language of adherence to medications and compliance with health care advice was continued by a physician speaker who focused on the importance of behavioral intervention for maximizing the benefits of health care. In both talks, the speakers tacitly prompted audience members to conceive of health as an individual achievement or failure to effectively follow the rules and procedures of medical care. In another conference designed for the HIV positive community, adherence to social prescriptions concerning health was reinforced through notions of leadership, advocacy, and an eminent decline in federal funding for support services.

At the second community-wide educational conference I attended, the keynote speaker suggested that HIV positive individuals need to take control of their lives, their health care options, and public perceptions concerning HIV disease and the epidemic. The keynote speaker asserted that the TMA was a restrictive and temporary moment in Ryan White legislation. The loss of funding for support programs such as transportation, advocacy services, and emergency assistance was unacceptable to HIV/AIDS advocates. He argued that this legislative inadequacy could be rectified by changing popular perceptions concerning HIV positive individuals and constituents.

The speaker explained that HIV positive people are often placed into roles based on assumptions made by health care providers and support services employees. These

roles include that of a medical subordinate, medically non-compliant, and/or politically inactive/uninformed. He explained that these assumptions were reinforced when HIV positive people could not or did not effectively navigate the system of care and treatment. Consumers of care and services, he argued, need to develop dual personas of "public self" and "private self." These dual images could change perceptions of HIV positive people and thus the social dynamics through which their treatment is provided. The "public self," in this scenario consisted of an individual who had developed leadership skills and the ability to advocate for others and one's self. The "private self" was presumably the person stripped bare of advocacy responsibilities and skills. Above all, he cautioned, "attitude is everything." He spoke of the difference between arguing for an idea and requesting particular actions in comparison to making demands. Both strategies are needed in HIV politics. However, he asserted, HIV positive constituents need training, self-motivation, education, and support in order to use these skills effectively. The responsibility for changing the terms of Ryan White funding and HIV treatment, it seemed, lay in the interactions between support services staff and consumers of HIV medical care and related services. Change in this way theoretically began within Health Partnership when they began teaching clients how to effectively navigate current structures and relations of care. Behavioral change techniques were largely aimed at the creation of functional relationships between clients and service providers. This strategy of behavioral modification provided an important means whereby women learned "the rules of the HIV/AIDS care game."

The notion of creating a working client/provider relationship through behavioral modification was implemented in a women's-only workshop during this particular educational conference. The workshop was an off-shoot of Health Partnership's women's HIV support group. The support group itself was designed to allow women a space in which they could explore strategies for and experiences of self-love, self respect, and self-determination. These strategies would theoretically help to achieve health in five dimensions: spiritual, physical, emotional, social and intellectual. The workshop focused on strategies group members felt were effective for navigating their relationships with service providers throughout the care continuum. Keeping one's voice quiet, respecting appointment schedules, asking for help rather than telling a provider they will

help, and accepting responsibility for "those things we can control[xxii]" were all discussed as potential sources of success in traversing the system of care. At the core of the workshop was the idea that if women come to service appointments with anger and/or mistrust, they will be met with resistance. Although the workshop conveyed useful skills for navigating the interpersonal dimensions of client/provider relationships, the focus on these particular skills suggested that some women perhaps deserve the poor health care outcomes they experience. The focus remained on the individual rather than the systemic relationships in which individuals are embedded. This individual-level perspective could facilitate the achievement of women's short-term service goals. The workshop facilitator thus emphasized women's personal responsibilities and capacities to modify their behavior. She said,

> …aggressive behavior turns into a flight or fight response for the recipient of those aggressive words. Be assertive and in control, but use a voice and body language that is non-threatening. Otherwise, your outcome depends entirely on someone else's reaction to aggression (Felicia).

While the workshop facilitator encouraged women to assert their opinions and voice their concerns, she conceded that those efforts alone were not always enough to maintain functional relationships with providers of care. She urged women to be "aware" of one's self. She asked that they learn how and why one makes the choices one does. She further implored participants to use an "acceptable" style of communication. Knowing oneself and one's communication style are the first steps towards learning how to build healthy relationships with others. In turn, she argued, "building healthy relationships is a means of resisting control by others who don't want what's best for you". Women were urged to resist the power and control that boyfriends, family members, and/or friends might have over their lives. Instead, women should cultivate positive relationships with family and friends while severing relations that result in unhappiness and negativity. Resistance to negative social influences began with adopting values and behaviors sanctioned by providers of care.

Taken together, educational forums and conferences in Midway conveyed a community-wide concern among service providers for individual responsibility for one's health care. This concern was conveyed through teaching strategies for the facilitation of working client/provider relationships. Ideals of decorum and self-management were

implemented as behavioral modification techniques aimed at building institutional "networks of care" for HIV positive individuals. In the end, success is defined by the Treatment Modernization Act as treatment adherence and desirable health outcomes. This success depended largely on women being able to build a functional institutional network to which they turned in times of health need.

The lessons taught and learned through community educational programs mirror notions of reciprocity, support, and mutual aid that are often found among African American informal social networks (see Naples 1998; Newman 2001; Stack 1974 and 1982). Women were urged to consider themselves as one part of a larger system that would run smoothly if based in principles of mutual trust and respect. Women were also urged to "give back" what they received in the sense that they, as participants in the system of care, were obligated to act in the best interest of the broader HIV-related community. It was through these behavioral guidelines that institutional network strength shaped women's health-related needs and health statuses.

Stable Women and Social Network Surrogacy

The system of care operated beneficially for women who were able to create and maintain personal ties of obligation and/or trust with programmatic service employees. Personal ties of obligation and trust translated into increased access to resources. It is perhaps no surprise that, of the nine women considered here as "stable," seven are "regulars" at community events such as educational forums, conferences, retreats and support groups. Regular attendance at such events provided women with one means for meeting support service professionals. It also provided a means for learning the behavioral strategies condoned by community leaders and providers of care. In general, there were three tactics that stable women employed in their efforts to strengthen and transform institutional support networks. First, women actively sought to distance themselves from negative stereotypes and/or what are perceived as the negative attitudes of "ungrateful" clients. In some instances, stable women achieved distance from less favored clients by vocalizing their gratitude and mindfulness concerning how "lucky" they were to receive any assistance. Stacey explained that,

> I have no expectations because I was feel like—because the life that I led
> —all that stuff to me is like it's good. I really don't be expecting nothing.
> You don't know me from Alice's cat or whatever. I'm just glad you there
> to help at all (Stacey).

Stacey often subtly hinted that she should not expect to receive assistance because she is a former drug user. She turned this notion of "the undeserving" into a social advantage. Her "undeserving" status became a point through which she could communicate gratitude while recognizing the generosity of care providers. DeeDee similarly vocalized that she was thankful Health Partnership existed, even if she did not usually need to access financial or medical support services. In an interview she described this gratitude she felt,

> Nobody has to help you. Ever. You can be out there on your own. I just
> try to be thankful that I can get whatever little bit I can. I may not need
> money from them, but I can come down here and get my little food and
> just be thankful for that.

There is no doubt that stable women such as Stacey and DeeDee felt earnest gratitude for support and care they received from Health Partnership employees. It is true that, without Health Partnership, they would face financial crises and burdens with few options for support. Their feelings of gratitude were often discussed in relation to the purported non-gratitude of others. For example during our conversation concerning her feelings of gratitude, Stacey pointed out others' seeming lack of appreciation:

> I see some people that come around here, and they're cutting up, and they
> talk nasty and stuff. They feel like people owe them something. They
> don't say please or thank you. They just think that people there are
> there just to be serving them because they got HIV and they're mad about
> it.

To further distance herself from the non-gratitude of others, she explained:

> Well, people who are like that go just to get stuff—like when people get
> food and then they don't take it home. They going to go down the street
> and try to sell it. I feel like if you are thankful, then you should be using
> services how they supposed to (Stacey).

Stacey and DeeDee's strategies for communicating social distance from "other" women were adopted at least occasionally by most women in the stable category.

Social distance could also be achieved by pointing out one's own special attributes and skills. Joan described why she has a good relationship with her HIV case manager:

> Well she saw the things that I was capable of doing. She saw the skills, the way I talked, um me having a support group, my husband. The things we do, the resources we bring back to them—all of that. And that's when she opened up to me and I opened up more to her.

Joan described how she and her case manager grew close and achieved productive communication because the case manager found her to be compatible with institutional ideals concerning community involvement. While part of this understanding reflects Joan's skills and habits, it also reflects the way Joan endeavors to see the case management program from the perspective of service providers.

> Well me personally, I've seen clients complain about case management and they don't realize how much of a big load case managers have and they don't have patience—the clients don't. But they don't realize what they have to do. I'm the only one really that have her cell phone. So if I need something pertaining to my needs or whatever that need to be dealt with, I can call her. Because she knows that I'm not the type of person that's going to call her like 24/7 you know like I got a emergency situation (Joan).

Joan discussed her own perspective on the busy schedules of HIV case managers. She explained this perspective in relation to a presumed client norm. In this particular conversation, the norm represents a group of clients who are believed to have little regard or appreciation of the challenging work performed by service providers who have clients with intensive needs. Indeed, service providers often lamented that impatient clients lose sight of how much work is involved with providing assistance for chronic and multiple needs.

In other scenarios, stable women presumed the client norm to be best represented in terms of drug addiction and a seemingly endless need for financial support. Consider Debdai's explanation concerning why she believes she always receives the support she requests from Health Partnership:

> They know who's doing right and who's not. If I came in every month I could see. My record of not using the services is proof. Some times you have to look at the person and not by the book. But my no drug use speaks for itself. I don't take everything that's offered—just what I need. I don't even take everything they give me at the food pantry. I always

give back what I can't use or I already have. But, they continue to help those that aren't even trying (Debdai).

Debdai equates drug addiction with "not trying" to comply with behavioral prescriptions concerning the community good and personal gratitude. Her habit of returning food pantry items that she could not use and avoiding requests for emergency assistance falls well within the boundaries of what is considered by Health Partnership staff as appropriate usage of Ryan White resources. Health Partnership staff appreciated this type of "discretionary" service use because those resources could be distributed to someone who really needed them. A woman who accepted assistance with the intention of generating profit, giving resources to an HIV negative friend, or throwing them away would be considered as acting without regard for the greater good of the community and the financial sustainability of the organization. Building a history of socially appropriate service use in this way provided one means by which stable women could strengthen their institutional networks. These networks, in turn, wielded support even in times of financial stress among care programs.

For example, Charlotte needed rental assistance during a community-wide spending freeze on Ryan White emergency assistance funds. For close to three months, service providers struggled to assist clients with their housing and health needs. New contracts concerning housing and rental assistance programs for the new fiscal year had not yet arrived in North Carolina. Ryan White funds simply were not yet available for the new fiscal year. Rather than see her evicted or potentially succumb to further financial crisis, Health Partnership employees relaxed the rules. The new Ryan White contracts and funds were already in place for the medical case management/treatment adherence program. Charlotte's rent money was temporarily diverted from this account until it could be replaced by money earmarked specifically as emergency assistance dollars. In this way, Charlotte's strategic use of services and good working relationship with care providers translated into a best possible outcome in a context of resource scarcity.

In addition to the tactics of emphasizing social distance from "undeserving" clients and the community-minded use of services, stable women tended to be staunch supporters of volunteerism in the HIV positive community. Some stable women fulfilled

important community roles as support group organizers, CAB members, public speakers, and designated role models/mentors for women who struggled to adhere to medication regimens and/or recovery programs. Other stable women fulfilled important roles as HIV positive individuals who moved forward in their lives despite the diagnosis. Such women volunteered with children's literacy programs and church activities and/or continued to work in the professional and semi-professional world.

DeeDee, for example, was a professional woman who continuously sought meaningful employment. In her spare time, DeeDee volunteered for a children's literacy program at a nearby community center. She read to young children who could not yet read and tutored older children who found reading difficult. At the beginning of this research, DeeDee came to Health Partnership weekly. She would "stop by" just to help out with food pantry duties and general office maintenance. I often talked with her as she vacuumed, cleaned bathrooms, or helped unload shipments of donated food. After a few months, a program employee suggested that DeeDee take on a different type of volunteer role. Her excellent communication skills and her outgoing and jovial personality qualified her to act as a representative of sorts on behalf of the HIV positive community. This capacity led DeeDee to begin occasionally speaking at area high schools at about HIV prevention. She reported that her sense of humor, respectable style of dress, and young looks rendered her an effective speaker with respect to youth. She viewed herself as someone with whom young women could relate. In an informal conversation she explained that:

> Those little girls they just love me. They like 'oh Miss DeeDee we want to be like you when we grow up. You so fun.' I love it, girl, because I love kids. And they see that yeah I got this, but I'm like Tyra Banks—'so what.'

DeeDee enjoyed public speaking because she felt that her message reached a population that was often skeptical of adults. Her Tyra Banks—"so what" attitude sent a message to youth who might otherwise stigmatize persons living with HIV disease. DeeDee took pride in her resistance to popular stereotypes concerning low-income women with HIV. She believed her humor, stylish clothing, positive attitude, and desire to own a home flew in the face of popular and racist images that depict poor women of color as "house-shoe wearing, scarf-around-the-head women" (DeeDee). DeeDee's foray into the spotlight as

a public speaker transformed her volunteer status into what can be considered as a "professional volunteer."

Professional volunteer work in this context includes activities requiring particular types of skills and organizational habits because it most often took place at the intersections between the HIV positive community and the general public. Public speaking skills, knowledge of computers, and writing skills were the attributes most often required of women who performed volunteer activities in the public eye. Joan functioned as a full-time professional volunteer in the HIV positive community. She organized and led two support groups. She led one group that was specifically intended to meet the needs of women who wanted to move past their HIV positive diagnoses for the achievement of personal life goals. The group met twice monthly. In between meetings, Joan created computer-generated flyers. She distributed those flyers via email to different service organizations in Midway. She created meeting agendas and researched information concerning various clinical trials, educational forums, and resource opportunities in the area.

Women's professional volunteer activities were beneficial in a few ways. First, coordinating support groups, participating in CAB meetings, and public speaking put women into direct, informal contact with a variety of service providers. These opportunities allowed providers the chance to talk with women about things other than their financial needs or health concerns. Second, professional volunteer activities often indebted service providers to stable women in at least some small way. Agreeing to speak on behalf of Health Partnership and its clients at a public event took pressure off of providers because they found someone to fulfill the role. Organizing and running a support group through a particular organization could also be a means for garnering some financial support for the agency. When women took on the role of organizing such events, providers could use their energy elsewhere to benefit the community and the agency.

When considered in relation to stable women's community-minded use of services, volunteerism was part of what enabled stable women to occasionally utilize financial resources for what is legislatively considered as material wants rather than needs. "Material wants" includes items beyond food, shelter, clothing, and medical care.

As described in Chapter Four, stable women are categorically considered as low income by service providers and the federal government. Although many women described living in conditions of relative comfort, they still acknowledged and experienced their lives in the context of poverty. This meant that women who sought socioeconomic advancement needed programmatic services support to work for them in some "non-traditional" ways. Stable women tended to time their use of services for non-traditional needs to coincide with fiscal year spend-downs and/or contract reimbursements. These types of requests coincided with cash influxes. This meant that stable women's requests were not likely to keep other clients, perhaps with more immediate needs, from receiving services. Instead, their use of services could be regarded as community-minded in the sense that they were helping the organization to spend their funds so as to ensure that the next fiscal year would include at least the same amount of federal funding. Debdai, for example, utilized Ryan White resources for things other than basic health-related needs. In a conversation about her goals for the future, Debdai discussed how she wanted to learn how to travel on a budget. Debdai is a single mother of four grown children. Debdai has received welfare payments throughout her adulthood to help her afford life's basic necessities. She had never been able to travel as much as she would like. With the advent of Ryan White funding, however, she began to re-think her strategies for assistance requests. Debdai described that:

> I use these programs usually in the late spring or early summer because they allow me to do summer trips. You can think like if I can save like $80 or $100 a month, how a difference that makes. I can save some money for that because I go for assistance just like every two or three months. By that time, the bill has doubled so I can put all that money back. And then the you know the bill comes after it's been settled and I still have to pay that month's rent even though they've taken care of the other two or three months. But, there's no jeopardy for two months so you really end up getting four months leeway with your rent. You get more credit when you let the bill go.

As Debdai described, the strategic use of emergency assistance services enabled her to save money for summer vacations. Over the years she found that "letting a bill go" essentially meant that she would receive that much more in assistance funds. Using Ryan White services as a "last resort" before eviction, rather than as a last resort for a single month, allowed Debdai the opportunity to save more of her disability income. Debdai's rent is $82 per month, meaning that it would take her at least three or four months to save

the money needed for a bus trip to visit family in New York. While some service providers may view a trip home as a "non-essential" need, it was important to Debdai because it allowed her stay connected with family and friends. These social connections were an important part of Debdai's self-esteem and mental health. Maintaining these relationships meant that she had several individuals to which she might turn in times of emotional distress.

Although stable women did not typically have disposable income for non-essential needs such as car maintenance, vacations, and savings accounts, they improvised strategies for meeting these needs. Stable women operated in the context of a health care system that is partially based on ideas concerning adherence, client/provider partnership, and the responsibility for community volunteerism. In this context, strategies of distancing one's self from negative stereotypes, community-minded use of services, and professional volunteer activities enabled women to "personalize" their relationships with service providers. In turn, service providers could rely upon stable women to participate at community events and publicly demonstrate the efficacy of the programs they worked so hard to administer. Stable women were experts at negotiating access to support services precisely because they learned and transformed "the rules of the game," so to speak, into beneficial strategies for survival and advancement.

Temporarily (Un)Stable Women and Social Network Surrogacy

Like stable women, temporarily (un)stable women actively sought to build personalized alliances with case managers, counselors, and other service program employees. Temporarily (un)stable women were rarely met with overt judgment or harsh stereotypes by Health Partnership employees. Most service providers were acutely aware of women's sensitivities to popular imagery and negative stereotypes concerning poor women of color. Providers communicated respect and empathy to temporarily (un)stable women by committing their names to memory, asking about loved ones during informal conversations, and endeavoring to maintain accurate appointment schedules and client files. A general feeling of familiarity and conviviality permeated most client/provider relationships. However, temporarily (un)stable women were less effective than their

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stable counterparts in transforming programmatic service use into social networks. This was due, in part, to the failure of federal service provision mandates to accommodate temporarily (un)stable women's chronic service needs. In turn, women relied upon unsanctioned, and sometimes self-destructive, strategies for stability that excluded them from services.

Over the course of the research year, temporarily (un)stable women reported making, on average, four financial assistance requests. Women who were experiencing a downturn in their household conditions, substance abuse recovery programs, and/or economic circumstances clearly requested more support. Escalating requests for support were reviewed carefully by Health Partnership employees in relation to women's substance abuse issues, personal life circumstances, and service use history.

Health Partnership employees rejected "inappropriate" requests for assistance from temporarily (un)stable women. Central to the various ways in which women could potentially mis-use programmatic services was the concept of entitlement. Many women who felt ignored, short-changed, or unnecessarily excluded by programmatic service employees and procedure reiterated their technical "entitlement" to support. Kareese reiterated that:

> I ain't no stupid ass. I know that they got funds. They can find the funds to help you with. What they do with that money, I do not know. They make me feel like they got special ways. I know that they can't do nothing for me every month. I'm getting a check. But when you in a financial bind like me and [partner], and like they took some of his check out this month—70 dollars. That should have helped us because of that. That's they job. The money is there to help me. What the hell else are they getting paid for?

From Kareese's perspective, she has a right to claim a portion of Midway's Ryan White emergency assistance funds. Her right is based upon her HIV status and a demonstrable need for cash assistance. She sometimes reminded employees that their jobs were at least partially dependent upon her need for and use of services.

Kareese *was* technically entitled to support services. And, reminding employees of her technical right was a strategy for self-preservation in a context where she felt devalued and misunderstood. Health Partnership employees, however, reserved the right to refuse requests for assistance at any time. Indeed, Health Partnership employees had a responsibility to the organization and the broader community to use their program funds

in the most effective and fair way possible. In light of their responsibilities to counsel individual clients, protect the fiscal health of the organization, and further the broader goals of the community, employees saw "entitled attitudes" in a negative light. Consider what Natasha and Paula said about clients and the notion of entitlement:

> Entitlement—because I am positive. Because I am positive. I'm entitled to everything. They feel entitled to financial means, anything that goes under the definition of HIV without taking on the responsibilities of having HIV. No you didn't ask for it. No you didn't want it, but if you feel entitled to us paying your rent, then you must be responsible to go to your doctor's appointments. You must be responsible for handling your financial means to get assistance. …I'm sorry historically you've been able to walk through this door and get services upon your beck and call, but this is not Burger King and you don't get it your way (Natasha).

> You know people are very empathetic for you know to that person to say, "Oh, you know, I can only imagine what you going through." And you need this so they come in and start the pity party and everything is handed to them. But with me it's like I'm trying to get them to take some responsibility for themselves (Paula).

Paula and Natasha both described how they work towards ridding clients of feelings of entitlement to programmatic services support. Increased oversight measures in the Treatment Modernization Act circumscribe staff attempts to regulate how and why clients tried to access financial support services[xxiii]. The overall goal was to meet clients' needs in ways that did not break federal rules and guidelines. Otherwise, Health Partnership could face a loss of funding and federal and state contracts. Such a development would be catastrophic for clients and the broader HIV-related community. Providers' main strategy for dealing with "entitled" clients was thus to quickly and firmly deny any "inappropriate" requests or demands for support.

Muriel, for example, had long suffered financial hardship. In December 2007, she returned from a trip home to New York only to find that her house had been robbed. She lost everything, including the food in her cabinets, a television, appliances, and clothing. Muriel also dealt with a leak in her ceiling and the constant presence of mice in her apartment. She wanted desperately to move into a safer neighborhood and a nicer apartment. On $546 per month affording a new place to live was a difficult task. She also needed to replace the furniture she lost during the robbery. Affording a new

apartment required Muriel to devise a long term strategy for increasing her monthly income.

Muriel's long-term strategy was to re-establish residency in New York City. She planned to receive disability payments based on the cost of living in New York rather than in Midway, North Carolina. In her estimation, she would receive at least two hundred extra dollars each month, if not more. Muriel justified her plans by pointing out that she rents a storage locker in New York and so technically participates in the state economy. Muriel soon began putting her plan into action.

First, Muriel came to Health Partnership with a lease for an apartment in New York City. A friend mailed her a copy of the lease so that Muriel could find a way to make the lease appear to be in her own name. She used "white out" to erase her friend's name as the lessee. Next, she began asking employees if they could help her figure out how she could type her own name into the document. As Natasha, a case manager, prepared to "correct" the document for Muriel, she began question Muriel's plans. She asked, "What is it that I'm doing here?" Muriel vaguely responded that she needed a lease for her disability income claims. Natasha responded, "But this is a lease for New York and you live in North Carolina. No, I'm not doing this. I won't lie to the federal government for you." Muriel retorted, "I'm not asking you to lie. I'm asking you to type this for me. That's it. You don't even know what's going on." With that, Muriel left Health Partnership angry that she had been so quickly denied the help she wanted. However, from Natasha's perspective, what amounted to a client committing welfare fraud was potentially damaging to Health Partnership and, therefore, was not open to discussion.

In general, momentarily (un)stable women had inconsistent relationships with providers of care. In cases where women struggled monthly to secure support and make ends meet, relations were strained. Strained relations tended to remain "institutional" in nature, meaning that women could not count on service providers to be flexible with program guidelines. Institutional relationships, in this sense, are characterized by a lack of power sharing between providers and clients that might result in personal favors, professional or semi-professional opportunities, and/or increased access to Ryan White-related resources. Indeed, institutional relationships do not extend beyond the boundaries

of what could be considered in this context as "typical" client/provider relations. "Typical" relationships tended to be characterized by appointment scheduling guidelines and strict adherence to service provision procedures.

Temporarily (un)stable women also included women who could be considered as "on the upswing," or in the process of improving their daily life conditions. In these cases, small strides made in the personalization of institutional networks were momentous occasions, if usually short-lived. Lady E. represents one such case where changes in her service use strategies resulted in more personalized relationships with service providers. In turn, personalized relationships translated into increased access to health-related resources.

When I met Lady E., she had been in substance abuse recovery for about one month. She had zero income. She had long ago been diagnosed with AIDS, but her CD4 cell and viral load counts had been steadily improving. Lady E also suffered from a serious heart condition. She had recently undergone a ninth angioplasty surgery and suffered two heart attacks, one of which was drug related. In addition, Lady E "turned herself in" to local authorities for outstanding arrest warrants that were long ago issued. As a final step towards stability, a local mental health agency had been working with her to clear outstanding debts she owed to landlords and utilities companies.

Eight months into the research, Lady E had made dramatic progress in her recovery and with respect to her plans for the future. First and foremost, Lady E's HIV lab work indicated that she was no long in immediate danger for AIDS-related complications. With 400 CD4 cells and a viral load of only 1200 replications, she was comfortable with her HIV status. Lady E at this time rented a room in a boarding house. She felt the room was "a step backwards" in one sense because it was small and she had to share a kitchen and bathroom with strangers. Conversely, she acknowledged that renting the room made good financial sense. She had lived before in an apartment that she could not afford. While she had zero income, Health Partnership, social services, and a local mental health agency paid her rent. Now that her disability had been reinstated, she was expected to pay her own rent. She simply could not afford the apartment and her other bills. Moving into an affordable apartment signified an important step towards her future plans of financial stability.

In addition to securing an affordable apartment, Lady E. strategically used the disability back-pay she received. Her strategy paid off when she was recognized by service providers as a "responsible" person. She explained that,

> When I got my lump sum which was $1700, I paid for a burial plan. I paid for a computer because I really wanted it even though I couldn't afford the internet at first. I got a dining room set and I got a decent mattress for my bed because my back was always killing me. I didn't waste it away. And what happened was the workers came and they seen. 'She didn't get high. She didn't waste that money. She's still going to group. This is where her money went.'

Lady E's strategies for long-term financial stability and substance abuse recovery began to "pay off" in terms of access to financial resources. She was recognized by staff as a person who did not waste precious resources. She was newly positioned in the realm of services provision and reception as a client who had taken on the personal responsibility to abstain from illicit drug use, attend to HIV health needs, and properly manage financial matters. One Health Partnership employee noticed her efforts and provided her with the information she needed to obtain a small business loan.

Lady E next began taking steps towards receiving a small business license so that she could formally sell the beaded necklaces and bracelets she made. She hoped to turn her small business into an internet enterprise so that she could reach a wider variety of potential buyers. She managed a small business loan and a business American Express card. Lady E prided herself on being able to handle having that money without needing to go spend it on drugs.

Lady E's hard-earned sobriety and relative stability opened doors that she never thought possible. Health Partnership staff began supporting Lady E's business by buying jewelry and paying her to fix old pieces in need of repair. At one point, she estimated earning an extra $40 per week from agency staff alone. Some staff would refer friends to Lady E so that they could shop her jewelry collection.

In addition, service providers relaxed the rules for Lady E. She was now able to cancel and reschedule appointments, however late the notice, with no repercussions. In addition, the CRCS counselor felt comfortable enough to advance Lady E the fifteen dollar Wal-mart gift card she received for each CRCS session she attended. Paula, the CRCS counselor, knew that Lady E looked forward to her monthly gift card so that she

could buy new beads for her business. Lady E always made up her appointments and, because of that, the advances never became a service delivery problem.

A month before I exited the field, Lady E began experiencing small setbacks in her efforts to personalize and maintain institutional networks. Gas prices soared, grocery prices rose, and Health Partnership employees began feeling the crunch of the looming economic recession. Employees were no longer able to purchase Lady E's jewelry on a regular basis. She had come to rely on the extra $40 per week and was distraught when that money was no longer an option. Feeling the sting of being "dropped" by employees on whom she felt she could personally rely, she explained that,

> It just hurts because they knew I was relying on that. And then they just
> act like it wasn't no big deal. I know they do the best they can. They
> don't owe me nothing, but they could have you know talked to me
> about it instead of just dropping me.

Lady E. alluded to the idea that Health Partnership employees did not "owe" her any personal favors. She tacitly accepted that, although she had made progress in building an effective institutional network, program employees "owed" her nothing. The relationships she was cultivating were not based on reciprocity. Lady E provided employees with a valuable service when she repaired their jewelry and created custom pieces for them. However, this type of work did not create the conditions under which employees would become in some way indebted to Lady E. Community volunteer work was still the best option for personalizing institutional networks. However, temporarily (un)stable women found it difficult to break into the role most coveted by service professionals—that of the professional volunteer.

Temporarily (un)stable women did accomplish important tasks in their volunteer work. Lisa, for example, fulfilled the role of outreach worker for a local organization that implemented Medicaid and CDC-funded HIV/AIDS case management and prevention programs. Lisa's main task was to talk with people on the streets about safer sex practices. She also recruited small groups of people to attend "safer sex parties" hosted by this particular organization. For nearly ten years, she donated her time and energy to the organization. In partial compensation for her work each month, the organization gave her a $100 gift card to Wal-mart. Lisa endeavored to earn this gift card by recruiting otherwise disinclined groups to learn about safer sex.

One evening after a church service for the Black Church Week of Prayer[xxiv], Lisa talked with a representative of the church's youth ministries about scheduling a safer sex party. She explained that she performed volunteer work with a local AIDS service organization. The representative invited Lisa to call her later in the week if she wanted to talk in detail about the goal of the party. Later that week, Lisa called me to tell me that she had achieved the "biggest coup ever." The church was willing to schedule an event outside the Black Church Week of Prayer. Lisa did not get to organize a church-friendly safer sex party, but was able to arrange for this agency to provide an HIV/AIDS education and testing booth at the church's annual picnic.

On the Saturday morning of the picnic, I picked Lisa up at nine a.m. With a forty-ounce bottle of beer and a smile on her face, Lisa bounded out to the car. On the way to the event, she joked around that she should perhaps receive a prize of some sort for arranging an "AIDS event" on church property. Her face dropped when we arrived at the church. She did not see any of her fellow agency representatives. Church members bustled about setting up tents, popcorn machines, stereo equipment, and games. After about ten minutes, Lisa sat down on the sidewalk and started to cry. She lamented that "no matter what I do, they shit on me--just take it for granted that I'll come back." She reminded me that she had been overlooked at the Christmas party when other volunteers were recognized for their services. Lisa borrowed my cell phone to call the prevention program director. She cried harder when she learned that the service employees had changed their plans for the event without discussing the changes with her. When program employees did arrive more than an hour later, they failed to recognize Lisa's anger and frustration. I believe, in part, this recognition was due to the reality that Lisa was not a program administrator. I also believe this lack of recognition was a strategy for downplaying Lisa's outburst as stemming, to some extent, from her alcohol use. In any case, Lisa was upset and unable to see the situation from the perspective of the organization representatives. Lisa finally told them that she was "dropping them" and would no longer be a client at their organization. One employee responded by saying, "You always say that and you never do." It was several months before Lisa volunteered with them again.

As Lisa's story indicates, some temporarily (un)stable women found it socially and technically difficult to break into "professional volunteer" activities and relationships. This difficulty was in some ways the result of exclusion from important decision-making processes and in other ways was the result of personal choices women made concerning communication strategies. In other cases, addiction and/or depression made it difficult for women to "follow through" on long-term or intensive tasks and activities. However, providers continued to prompt women into service activities. Some care providers viewed volunteer work as a potential source of self-esteem that was presumed to be lacking in momentarily (un)stable women. Other care providers viewed volunteer work as an informal condition of services reception. As one case manager described part of her philosophy concerning the distribution of financial assistance,

> …if I help you, will you come help me get more money when we go speak at the capital? 'Well no I just can't deal with that. I can't deal with saying the words.' But still you have no problem coming through the front door not caring who's in the community when you have to get your rent paid. Some just think they are entitled to money because of a disease but not responsible to take on the entitlement for advocacy (Natasha).

Natasha explains that, in her estimation, if women feel "entitled" to receiving federally funded services through Health Partnership programs, they should also feel "entitled" to particular responsibilities. These responsibilities can include advocating on behalf of the broader HIV positive community and Health Partnership. Although temporarily (un)stable women did not often try formal volunteer work, they did perform needed work at Health Partnership. Women vacuumed, folded donated clothing, and cleaned the bathrooms as a way to "give back" to those who have helped them. Such gestures were noticed and appreciated by care providers, but did not stretch the boundaries of reciprocation in the same way as long-term professional volunteer activities.

Overall, temporarily (un)stable women struggled to transform institutional relationships into personal social networks. In some cases, women's service utilization strategies were considered by employees as inappropriate or indicative of an "entitled" attitude. Other cases, however, were complicated by continuing struggles with chemical dependency. Temporarily (un)stable women were not often able and/or were not often asked to participate in professional volunteer activities. The absence of such opportunities hindered women's efforts to personalize the institutional networks they

built through Health Partnership. Social networks, in the service provision context, remained institutional in nature. In turn, temporarily (un)stable women had fewer chances for receiving federal support provisions.

Vulnerable Women and Social Network Surrogacy

Vulnerable women struggled to little avail with the creation and maintenance of institutional social networks. As discussed in Chapter five, vulnerable women struggled to meet and maintain eligibility criteria for emergency assistance, disability income, Medicaid, and social services support. Disqualification for cash assistance services translated into diminished opportunities for sharing the personal life stories and information that sometimes created bonds between providers of care and Health Partnership clients. Disqualification also meant fewer opportunities for vulnerable women to exhibit personal responsibility through appropriate service use. Vulnerable women did, however, solicit personal favors from care providers by explaining their dire circumstances. For example, Jamie strategically used her status of diagnosis with AIDS in order to persuade care providers to help her. She explained that:

> …you have to roll out your symptoms and your sad story to get help at
> most of these places. Here you already know that I'm HIV positive so you
> know why the help is so important and what it means. But you know they
> can't always do it. They got their rules too. So I have to say all that about
> the diarrhea and tell my AIDS story again. And, if I misused the funds I
> have with extra curricular activities, then I may have to kind of like
> explain myself and tell the story again. They want to help. You just got
> to like convince them to bend the rules a little sometimes (Jamie).

Jamie discussed how her technical disentitlement from many cash assistance services could be alleviated by appealing to providers' sense of empathy and compassion. This strategy did sometimes work precisely because Health Partnership employees generally cared about clients' well-being. Providers of care did want to prevent and/or alleviate any suffering that a client might potentially experience. However, such a strategy could only work when employees had extra or ample resources at their disposable. During agency- wide "spend-downs[xxv]" or given a donated sum of money, employees could

afford to "stretch the rules" for an unsanctioned need such as disposable undergarments or cash assistance for a technically ineligible client.

Given their technical ineligibility for federal emergency assistance funds, many vulnerable women relied upon Medicaid case management as their primary source of health-related services support. In relation to Health Partnership's Ryan White-funded programs, Medicaid case management was designed as a point of access and care retention. Medicaid case managers could request support on behalf of women, verify eligibility for services, and witness or assist with women's compliance with procedure and policy. Vulnerable women most often discussed Medicaid case management, however, as a continuation of the barriers they faced for utilizing Ryan White programs.

Nine out of eleven vulnerable women reported working, sometimes unwittingly, with non-medical case managers from the various Medicaid-funded organizations in Midway. Many times women described how they "hired" case managers. They reported giving their new case managers copies of their Medicaid card during their first visits. First visits were also a time for discussing women's living situations, substance abuse issues, and future goals. Some vulnerable women would soon find, however, that their new case managers thereafter stayed permanently "out of reach" until it was time to re-certify. Sharon explained why her case manager purposefully avoided her phone calls and impromptu office visits.

> I been calling my case manager and I don't hear nothing. She say I got to take my social security and turn it over to them and let it be in their name. Well I'm willing to do that if they hurry up and give me a place to stay. I'm just beat. I don't get no rest with where I'm staying (Sharon).

As Sharon explained, her case manager refused to work with her until she formally designated her case management agency as her payee. The payee role played by some case management agencies was sometimes questioned and criticized by Health Partnership employees. Rumors circulated among Health Partnership clients and staff that some payees pooled clients' disability checks instead of keeping separate accounts. This potentially meant that some clients did not always receive the full cash benefits to which they were entitled. Sharon was so uncomfortable living with her brother that she seriously considered voluntarily relinquishing her monthly check to her case manager despite these types of accusations and claims.

Vulnerable women also heatedly discussed how when they did meet with Medicaid case managers, it was unfruitful. Women requested that their case managers provide them with technical and emotional support while they tried to enroll in Ryan White-funded and other such social service programs. These interactions were too often viewed as unhelpful and sometimes demeaning. In some scenarios, vulnerable women felt as though case managers shirked their responsibilities towards women by simply referring them to Health Partnership for their needs.

> They ain't worth no two damn cents because they send us over here [Health Partnership]. And we came here first, you know. They send you somewhere you already been turned down at, know what I mean? You got all those people working there and the most thing I can get out of there is a couple of bags of food. But other than that, oh well we send you somewhere. So basically you're doing your leg work (Tasha).

Tasha explained that her Medicaid case manager tended to provide her with referrals rather than actually assisting with support requests. She further questioned what the point of having a case manager was if not to physically assist women access services and programs. Chantelle had long since stopped trying to work with case managers whom she perceived as unconcerned with clients who were relatively poor in relation to other clients. In Chantelle's estimation, her experiences as a chronically homeless woman with no means of income generation translated into social devaluation.

> Well how about this here I was asking my case manager for help getting me housing, finding a job, helping me stay clean. I got a termination letter from the social security place—from disability. I didn't understand what it meant and I went to my case manager's office. I said excuse me, I need to see you. She said, 'later Chantelle. I'm too busy for you right now.' And you know what, five years and you haven't got me housing, you haven't got me a job, I haven't gotten any money. What are you doing for me? Seemed like you basically helping the people that got money. I'm the one that don't have. Help me ok?

Chantelle was told that her case manager did not "have time" for her at the moment. She points to that remark as the pivotal moment that determined the dissolution of their client/provider relationship. However, that particular moment was more or less reflective of the dynamics that had taken place for five years. Chantelle re-certified every year with her case manager, regularly requested assistance, and utilized the food pantry at the Medicaid case management agency. However, she was still not positioned to be

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considered as a service priority because she lacked a lease and utilities bills in her name. The services she could receive were limited because of this. Until she achieved sobriety and documentation of her residency or ability to pay rent, there was not much a case manager could do for her in the way of financial support.

Rosalind encountered a similar experience when she signed up for Medicaid case management. She more generally lamented that,

> I quit her and now I'm my own case manager. What do I need you for? For you to work my Medicaid card? You know but they do bring by food and then they write out plans and stuff for you, but those plans stay that way—just written down (Rosalind)

In Rosalind's estimation, Medicaid case managers function to "work" women's Medicaid cards, meaning case managers bill Medicaid for services not provided. Many women were skeptical of case managers in this way, regardless of their social and economic positions within the broader system of HIV care and support services. Vulnerable women felt this potential dynamic acutely in the context of their own suffering. As a further insult to their senses of justice and fairness, case managers were sometimes admired by Health Partnership clients for their "nice cars," and "fancy clothes." Tasha mused aloud that, "my Medicaid card probably bought that nice little shirt."

In this context, vulnerable women's relationships to Health Partnership were situational and, in the end, financially unsustainable. Vulnerable women were sometimes able to garner support through programmatic services during times when resources were relatively plentiful. That support, however, often stopped short of truly meeting women's needs because vulnerable women's needs were far more intensive than what federal guidelines were designed to cover. In the months before I met Georgia, for example, she lived in an apartment. She and her partner were evicted for non-payment of rent. Social services pledged to help Georgia secure the deposit for another place to stay. In the meantime, she and her partner rented a room for $400 dollars per month in a boarding house. A few weeks into their stay at the boarding house, fellow tenants robbed the house of the stove, refrigerator, and furniture. The heat was turned off for failure of payment to the gas company. The landlord did not respond to Georgia's phone calls requesting he address these problems. Realizing that the winter months would bring increasingly cold weather, she and her partner accepted the assistance from social

services and moved into a new apartment. At the same time, however, Georgia lost her disability income. Georgia worked as a hotel maid for close to six months before leaving the job because she was accused of stealing from the cash register. Her eligibility for disability income was discontinued because she did not report the income she earned while employed.

Health Partnership and social services together tackled Georgia's financial needs. They paid her rent in its totality for three months while her partner paid the utilities bills. Yet, Georgia's financial situation did not improve over the three months she was able to receive emergency financial assistance. She and her partner tried to earn extra money by selling items found in the trash and in abandoned homes. The little money they earned from that, she explained, was sometimes used to buy crack. Georgia's chemical dependency issues were known by Health Partnership employees. Indeed, Health Partnership is one place where women can candidly discuss their struggles without of fear of legal repercussions. Georgia's substance abuse issues did, however, mean that service providers would "keep a close eye" (Bert) on how much support she received without demonstrating a change in her ability to manage her own money and support herself. Despite that she was not yet stable and reinstated in the disability insurance program, Georgia was cut off from emergency assistance funds until she could demonstrate progress in substance abuse recovery or income earning strategies. Proving that assistance resulted in some sort of "progress" in terms of her living conditions and capacity to care for herself was necessary for justifying the organization's spending and budget request for the next fiscal year. In short, Georgia's experiences exemplified the strategies through which Health Partnership employees guarded against "enabling" and being accused of "enabling" clients to continue using drugs. In turn, such strategies exemplify the federal policy and local service dynamics through which vulnerable women negotiated requests for financial assistance.

In addition, vulnerable women who were perceived as ungrateful, irresponsible, or inappropriate, were quickly "put in their place" by fellow clients who were well-positioned within the care continuum. Elizabeth's experiences provide one example of how vulnerable women could be "put in their place" given a less than optimal situation. When I met Elizabeth, she had just been released from jail for assault charges. As we

talked, Elizabeth sat across from me with her hands folded in her lap and a mild smile across her lips. She was calm and collected as we discussed her living conditions, despite the stressful situation. Upon release from jail, Elizabeth learned that her husband moved into a new rental home without telling her. She went to their old address and found him gone along with her clothing, furniture, and personal items. He did not call, visit, or write while she was incarcerated. She began asking neighbors, friends, and relatives if anyone knew where he had moved. Finally, a family member gave her the new address. Elizabeth went to the house and "re-claimed [my] place in our family." She reported that her husband was surprised to see her, but he did not resist her moving in to the new home with him. Though she felt "a little embarrassed" that he would move without telling her, she was determined to stay positive about the situation. After all, she said, "He's my provider. He pays our bills and makes sure we got food to eat."

A few months after our initial interview, Elizabeth began publicly venting what appeared to me as frustration and anger. Her husband was working only sporadically and they had trouble affording rent and utilities bills. Elizabeth tried to volunteer at the food pantry as a means of gaining increased access to food. Her strategy was quickly shut down by the nutritionist because it was unfair to other clients who did not or could not volunteer. Elizabeth's uncharacteristic outrage prompted employees to wonder if her behavior meant that she had begun smoking crack again. This idea was reiterated one afternoon when she grabbed a donated purse out of Raquel's hands claiming that she "wanted it from when it came in last week." She dared Raquel to take it back from her. When Raquel declined to argue and fight, Elizabeth began to loudly discuss the reasons why she "hated" one of the Health Partnership employees. She called the employee "a conniving bitch who thinks she rules the world." Elizabeth warned other clients not to trust her.

Soon after this incident, Elizabeth was banned from receiving services at Health Partnership. DeeDee, one of the stable women, told the director of client services that she witnessed Elizabeth stealing a large number of bus tickets from their hiding spot. DeeDee had herself been once painfully accused of stealing from Health Partnership. She had also related to me that she hated "Elizabeth because she [is] an uppity bitch." Without any formal grievance process, Elizabeth lost her privileges at Health Partnership.

She could not request assistance or utilize the food pantry for six months. In this case, Elizabeth's inability to use strategies for effective communication and community-minded service use served to further disenfranchise her from federally-funded HIV health services.

Overall, vulnerable women's inabilities to use institutional ties as a surrogate social network emerged from federal policies that did not reflect the social dynamics of physical vulnerability or the financial dynamics involved with addiction and incarceration. This lack of policy recognition concerning variations in the conditions of poverty made it difficult for service providers to attend to vulnerable women's needs without "bending the rules" and thus endangering Health Partnership's relationship with state and federal funding sources. Federal policy guidelines instead favored women who were better positioned to display normatively middle class values, behaviors, and strategies for health and survival. Such a dynamic meant that African American women living with HIV disease in Midway experienced differential access to HIV-related services and programs designed to distribute material goods and cash assistance.

CHAPTER SEVEN:
"THEY READ IT [THE TRUTH] IN YOUR BLOOD:" NEOLIBERALISM, DIAGNOSTIC TECHNOLOGIES, AND PERCEPTIONS OF HEALTH OUTCOMES

The HIV positive African American women who participated in this research were intelligent and creative daily life strategists. The conditions under which they sought to achieve material stability and social network viability were challenging. Strategies for health promotion such as stress reduction, adherence to medication regimens, and the building of networks conducive for access to health-related resources did not emerge from a perceptual vacuum. Rather, meanings associated with the medical category "HIV disease" was re-cast and re-made through experiences of illness and social relations (Lock 1995; Meyers, Leonard, and Ellen 2004).

In this chapter I illuminate how women's perceptions of survival with HIV disease were shaped by social processes in which women participated within the system of care. In turn, I examine the ways in which experiences of survival shaped how women perceived the medical category "HIV disease." I argue that women's immediate needs provided a perceptual filter through which they came to terms with the impact of illness on their lives. I further consider how women's experiential knowledge concerning HIV disease was mediated by a service provision context shaped by neoliberal ideals of self-management and personal responsibility.

"Regulating the Poor" through Public Institutions

Foucault (1991) uses the concept of governmentality to explain how government policies and practices shape the citizenry[xxvi] in ways that are beneficial to the state. The shaping of populations, he explains, happens through state-level policies and practices that are administered at the level of institutions. Such institutions can include hospitals, social service offices, and schools. In the context of neoliberalism, public institutions focus, in part, on the inculcation of ideals for self-management. The Personal Responsibility and Work Opportunity Act (PRWORA) represents one such body of policies whereby government-sanctioned ideals of self-management are instilled.

As discussed in Chapter Two, policies that promote privatization, market deregulation, and public services disinvestment are the cornerstone of a neoliberal agenda. In this context, policy makers have sought to re-organize the citizenry by compelling the poor to take charge of their own lives (Goode and Maskovsky 2001). "Compelling" the poor, in this sense, means forcing them into the labor market through restrictive welfare policies and lifetime eligibility limits. Moving people off of welfare has been understood as a "smart" policy that can potentially free the federal government from "unnecessary" spending (Kingfisher and Goldsmith 2001) while speaking to "the basic American values of work, family, responsibility, and opportunity" (cited in Lehman and Danziger 2004:603).

By arguing that the welfare system *promotes* "parasitic" behavior, policy makers and analysts assert that a system that provides assistance indefinitely hinders the development of personal capacities to realize proper personhood and "citizenship" (Kingfisher and Goldsmith 2001:714). Citizenship, in this sense, means the "citizen-worker" who has rights as economically productive and, presumably, "rational" individuals (Kingfisher 2002:25). Through this discourse of the citizen as worker, unemployed African American women have been publicly positioned as "welfare queens" who manipulate "the system" simply because they can (see for example Seccombe 1998). Welfare is then cast as a means through which poor women become "pathological" non-citizen subjects in need of behavioral intervention, rather than as a means through which poor women receive compensation for their reproductive labor. In turn, welfare reform becomes the mechanism through which the U.S. government can "liberate" women from the poverty and social ineptitude that the welfare state is envisioned to have produced.

In this discursive context, policy makers and pro-reform officials of the early 1990s sought to "end welfare as we know it" (cited in Lehman and Danziger 2004:603). And, the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 did just that. PRWORA replaced AID to Families with Dependent Children (AFDC) with Temporary Assistance to Needy Families (TANF) and, with that replacement, changed the eligibility requirements and distribution process of welfare benefits to the poor. Where before AFDC provided immediate and transitory assistance

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for women and their children through cash assistance, food stamps, and Medicaid enrollment, TANF decoupled cash assistance from Medicaid enrollment, eliminated the *entitlement* to cash assistance, limited lifetime eligibility to five years, and mandated that women work in exchange for their benefits after two years of enrollment (Good and Maskovsky 2001; Morgan and Weigt 2001; Lehman and Danziger 2004:606).

Policies such as PRWORA that are aimed at re-conditioning social citizens as economic citizens emphasize strategies for acculturating the poor to market conditions (Lehman and Danziger 2004). This political shift is bolstered by the notion that the state should function to allow people to become economic citizens by "freeing" them from the "burden" of welfare "dependency" (Goode 2002; Lehman and Danziger 2004; Goode and Maskovsky 2001). It is in the mechanisms of shifting responsibility to the individual that neoliberalism can be understood as a series of strategies aimed at "regulating the poor" (Maskovsky 2000).

AIDS Care and the Neoliberal Subject

In the neoliberal context, the goal of federally-funded AIDS care is, in part, to control the epidemic by educating HIV positive individuals on proper care of the self and providing a temporary means for that care. This view of public health service is not new. Public Health campaigns and programs have long been understood as being concerned with regulating bodily practices for disease prevention and collective safety (Foucault 1994; Lupton 2003). From internationally-funded vertical health programs aimed at eradicating disease in lesser-developed countries (Kim et al. 2000) to the normalization of prenatal diagnostic screening (Browner and Press 1995), public health programs have long been theorized in relation to their role for discerning the human body as a site for the exercise and expression of disciplinary power (Foucault 1994; Lupton 2003).

This is not to say that public health programs do not operate to save and improve lives. Indeed, public health goals and programs are often based upon notions of advocacy and social justice for poor and disenfranchised populations (see for example Geronimus et al. 1996; Heggenhougen 1995; Inhorn 1995; Krieger 1999). Ryan White CARE Act programs, for example, have undeniably increased access to life-saving heath care and

anti-retroviral therapy among poor and uninsured populations (Abramson et al. 2002). Although rates of AIDS diagnosis continue to rise disproportionately among poor women of color in the South, public health programs increasingly seek to address the conditions of this disparity through fostering access to resources such as health care, housing, and other such basic needs (Kaiser Family Foundation 2007). The Treatment Modernization Act can be understood in this context as a crucial public health response to health inequalities. However, the perhaps unintended consequences of public health programs cannot be overlooked. These unintended consequences provide one means through which individuals become politicized in the popular imaginary as neoliberal subjects who are in need of behavioral intervention and related support.

Publicly-funded AIDS care programs conform in some ways to the demands posed at the intersections of neoliberal ideology and medical treatment for HIV disease. Black women, in this conceptual space, are envisioned by policy makers and funding agencies as potential health outcomes in need of behavioral intervention. Conversely, service providers are positioned by policy makers and funding agencies as agents and/or allies of the state who are charged with federal managing funds and resources in ways that reflect the values and goals of governing institutions. Notions of self-care and disease management in the neoliberal context becomes one means for satisfying ideals concerning the government divestment of public services and social supports (Foucault 1991) while simultaneously meeting the material and health needs of a vulnerable population.

"Proper care for the self" in the context of HIV care includes adopting safer sex practices, drug use cessation, paying one's bills on time, and adhering to nutritional advice, to name a few strategies. All of these strategies promote HIV-related health. This is reflected in that the measure of success for programs designed to change the behaviors of poor and HIV positive populations is the relative health of individuals over time who are enrolled in programs such as those provided by Health Partnership. Health, in the context of this research, was measured in terms of CD4 cell counts and viral loads. Each physician visit ideally included the drawing of women's blood for "blood-work." Each physician visit also ideally included a discussion or brief report of the blood-work drawn at the previous visit.

Women were prompted by their physicians and support service providers to understand HIV disease in terms of laboratory work. Laboratory reports provided a "window" (Rapp 2000:29) of sorts onto women's health practices. However, the meaning of this laboratory work depended upon the network of individuals for which those laboratory reports had relevance (see Latour 1979:110). For care providers, these numbers were a means of tracking the efficacy of their services. State-mandated software programs[xxvii] charted CD4 cell and viral load progress over time in the form of a line graph. The line graph, when viewed in relation to the services utilized by a given client, was perceived as an indication as to whether programmatic services achieved AIDS prevention or the recovery of health.

For physicians, one's laboratory "numbers" provided a reference point for thinking about medication efficacy or adherence, drug use cessation, and/or stress reduction (Moore et al. 2001; Rosengarten et al. 2004). For example, lab work that indicated decreasing CD4 cells and an increasing viral, over the course of two or three months, could suggest that a woman's medications were no longer effective or that some of her daily life conditions were incompatible with the course of treatment. "Daily life conditions" could include not taking medications as prescribed, illicit drug use, chronic stress, and poor nutrition, among other factors. The general theory among service providers was that "good" lab numbers indicated that women were living lives of compliance with behavioral prescriptions concerning health. In this context, women would often return from physician's visits pondering their latest "numbers" and what they meant in terms of their strategies for health. The intersections between laboratory work and evaluations of health behaviors provided a conceptual space in which some women shone as models of program success while other women were cast as "challenging" or "hard to reach" clients.

The juxtaposition of laboratory analysis and daily life is not a new concept. Rather, Petryna (2002) points out that the dynamic interplay between scientific and social phenomena come to define the actual conditions of health. Her work among Chernobyl survivors illuminates the ways in which biomedical research practices can reify particular experiences of suffering while negating others. Biehl (2005) similarly explores how medical diagnostic categories play a key role in determining a sense of being and a sense

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of value for others. He argues that medical categories help to determine which kinds of lives society supports (2005:9). In both arguments, biomedical knowledge is considered in relation to the social, political, and moral contexts of daily life (see also Rapp 2000). Practices of biomedicine, in other words, play out on a complex social terrain (Rapp 2000:5).

Perceptions of HIV disease cannot be fully understood without understanding the local contexts through which social actors define health (Lock 1995). In this study, women articulated their perceptions of HIV disease in ways that simultaneously spoke to the realities of their daily lives and neoliberal ideals of personal responsibility and individualism. Laboratory work and biomedical categories of illness, in this context, operated as a backdrop against which women elaborated situational conceptions of the disease where the meanings of HIV disease were contingent upon women's life circumstances.

Stable Women and Perceptions of HIV Disease

Across the board, stable women tended to most often discuss HIV disease as a technical detail of life or a health inconvenience. Stable women explained that "most days it's [the HIV] like it's not even there" (Charlotte) because they did not feel physically sick. In the absence of illness symptoms, women reported only "remembering the HIV" when it was time to take their medication. The feeling that HIV was "not even there" was bolstered by women's participation in community educational activities.

Stable women's participation in support groups, community events, and personalized institutional social networks gave them ample opportunities for discussing HIV disease and adopting philosophies of survival sanctioned by Health Partnership employees. Health Partnership employees prompted women to view themselves as "more than this disease" (Natasha). Despite that the state tracked service provision "success" in terms of women's CD4 cells and viral loads over time, care providers unofficially sanctioned an alternative view of success. As Natasha explained,

> Let's get to know what a CD4 cell is and let's get to know what a viral
> load is because those are the two things you will be talking about. But,
> we're not going to utilize that as a lifestyle. Just because they say "fine"—

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I want you to know what "fine" means. I want you to know more than just
those numbers. Is "fine" just those numbers? I want you to know the
whole aspect of your health. How do you *feel*? Is your life working for
you?

According to service providers, the "whole aspect of your health" included anything that potentially caused stress and unhappiness in women's lives. The question of whether "your life [is] working for you" asked women to reflect on personal circumstances over which they had at least some control such as employment, drug use habits, and relationships with family and friends. Not using numbers as "a lifestyle" suggested to women that "good" HIV labs are not enough to achieve health and happiness.

In women's estimation, however, laboratory work *could* alleviate the stresses and strains of daily life when it indicated that women had the HIV "under control." "Good lab work" indicated that women were healthy enough in their lives to take their medications as prescribed and maintain their health at a level conducive to bodily comfort. Health Partnership staff acknowledged this reality, but wanted women to "take that next step" and maintain stability without programmatic service use.

In partial credit to Health Partnership programs and employees, the women in this study were all enrolled in health care. All women in this study were also under the regular care of a physician. Not all women, however, shared the same perceptions of HIV disease and their prospects for long-term survival. The extent to which women's perceptions of HIV disease and health care practices were "regulated" through programmatic services depended upon their abilities to access health related resources.

Stable women were best positioned to access health related resources such as affordable and safe housing and income assistance. The conditions of this relatively advantageous positioning translated into positive understandings of HIV disease and the potential trajectories of their health. When asked to consider their disease course over time, stable women responded with statements like,

I have the most thing that bothers me the most is my wear and tear arthritis.
Because that has hindered me more than my HIV. My HIV hasn't hindered
me—that's the least of my worries. I've already rearranged my life to that
style. It really doesn't bother me no more. I know I'll be around (Debdai).

That's the one area of my life—it's like if my car would behave like my
being HIV positive, I wouldn't have no problems. I have never had any

flare ups, any symptoms, any nothing. Nothing but the fact that someone else told me that I am HIV positive and I take medication. …It just has no barrier on my life and I don't see that it ever will (Charlotte).

Stable women, such as Debdai and Charlotte, tended to explain their outlook on HIV disease in relatively optimistic terms. Though most of the stable women in this study mentioned at some point that they would rather live without HIV infection, they felt as though it did not pose too big of a burden on their lives. Tamara, for example, described that she perceives HIV disease as less cumbersome than other chronic illnesses:

> I realize that is not—from all the groups that I've been to and all the support groups I've learned that even if I didn't have HIV, nobody knows when you're going to die. Because the medication you know —the disease is treatable. And HIV is less worse than diabetes, cancer, hepatitis. I say, 'you know I'll die when god is ready to take me, not because HIV is ready to take me out' (Tamara).

Tamara explained that HIV disease occupies a marginal place in the physicality of her daily life. Were it not for the actual ingestion of medicine, stable women explained that they could live through an entire day, week, or year without "feeling HIV positive." The notion of "feeling HIV positive" was explained by women in terms of the emotional and physical discomfort they felt soon after their diagnoses with HIV disease.

For example, stable women described their early experiences with "feeling positive" in terms of the emotional distress that symptoms and social strain caused them. Tamara discussed her early experiences with the emotional distress that the HIV positive diagnosis initially caused her:

> And um to me that was like that drug addict's disease, the prostitutes'—it was their disease. I went through a period of feeling very disgusted with myself. I was having sexual issues, you know, with having sex with my husband. You know there are things out there like, you know, the dental dams. But, I heard some suggestions at group from other people that you could use saran wrap. It's clear, it clings to your body and it's more natural because that's just something you have around the house. So we opened it up and I put in between my legs and I thought, 'oh my god. We are putting plastic on me because I am contaminated' (Tamara).

Tamara's initial feelings of contamination were intimately tied to her perceptions concerning HIV risk and the public health construction of HIV risk groups (see Farmer 1996; Treichler 1999). Because she was a woman who had never used intravenous drugs or exchanged sex for money, she was unsure how to interpret the manifestation of HIV

disease in her own body. The virus became a source of disgust and social and physical distance from her husband. Over time, however, support groups, counselors, and friends living with the virus helped her to come to an alternative way of thinking through the HIV disease.

> I—most of the time I go about life like I don't have it. I don't dwell. I mean I think like I have HIV or AIDS—whatever you want to call it. And I'm like oh my god. I have the most—I have the monster. But I'm saying, 'you know what? That monster is not bothering me and I'm not bothering it.' I have little army men inside of me. They are fighting this monster and this monster is hiding from all of the little army men that are in there. This is a battle. … They need canons. It's like a parachute drop. They need their grenades. They need their bullets so I take the medicine and there you go. It's empowering to know I provide them with what they need (Tamara).

Tamara explained a by-now ubiquitous concept inculcated through the intersections among American commerce and the health care system (Lupton 2003; Martin 1994; Songtag 1990)—that health can be achieved through "training" and "arming" the immune system for "battle." The time she was able to devote to building a network of HIV support service professionals and experienced peers paid off in terms of helping Tamara to re-conceptualize HIV disease as a condition over which she had control. Her personal responsibility in this context was to make sure that her "little army men" had the ammunition they needed to succeed in battle.

Overall, stable women perceived HIV disease in terms of an emotional journey through which they gained acceptance of their medical status as HIV positive. The journey, as they described, began with denial, fear, and, in some cases, anger or regret. Over time stable women learned to use the Ryan White system of care as a "touchstone" through which to remind themselves that they are more than their diagnoses. Stable women were able to stake their claims for resources, acceptance, and respect as "survivors [who] came out the other side to use it all to an advantage" (Charlotte). The system of care, in this sense, operated for stable women as a jumping off point for new life adventures and strategies. In turn, this jumping off point represented for stable women a new social and material position from which perceive HIV disease as but one part of their life.

Temporarily (un)Stable Women and Perceptions of HIV Disease

Some temporarily (un)stable women experienced HIV disease and care as a new found means for changing one's perceptions about life. After years of consideration and "soul searching," a few temporarily (un)stable women came to regard HIV infection as a catalyst for the many life changes made and experienced since diagnosis. Temporarily (un)stable women who experienced HIV disease as a "jumping off point" for new and desirable life adventures had made self-defined progress in their attempts to improve living conditions, health, and social circumstances. Lady E. explained her changing perceptions about living with HIV disease in this way:

> It's like I been getting high 25 years of my life. I have less because of it. I'm not less. You understand? I have less materialistic. I smoked up the mansion, the five car garage, the Lex, the Benz, believe me I have. It got to do with who you are and your purpose for being here. And I have to let them know, 'yeah 25 years of addiction. Yeah I got full-blown AIDS.' So what. I'm applying for Section 8 that's what I have collected in 50 years of living. That's not who I am. I am still good as gold and I know it.

Lady E. spent twenty-five years of her life wrapped up in what she described as "just being bad." A past that included "drinkin', druggin', and general mischief" (Lady E.) played an important part of her current outlook on living with HIV disease. It was the backdrop against which she measured her "progress" in recovery and health. With the support of her fellow support group members and social program employees, she turned despair into optimism for the future. HIV, in this context, was described by Lady E as "a blessing." In her estimation, physician and counselors statements about the potentially lethal combination of HIV disease and crack use prompted Lady E. to try living life without drugs. Lady E.'s "good as gold" statement was an affirmation engendered by Health Partnership's support group for women. Her experiences as a support group member who was in recovery changed an otherwise negative outlook on life with the virus:

> I began to [feel] better after talking through it. And it [group therapy] got to be a group for people with HIV because you can't go into any old support group for addiction and be talking about 'I got AIDS, I got Hep C.' …People are like 'you so fucked up anyway, what the hell. Go ahead and die of AIDS.' …I used to have a motto where I would tell somebody after I found out I was positive: "I got one foot in the grave

and the other one in quicksand. Come go with me." …I don't say that now. And that's what a group will do for your mental. I don't need to take anybody down. Matter of fact I'm not going either.

Lady E indicates that her perceptions of HIV disease changed over time. With the help of support group members and counselors, the HIV virus no longer represented certain death. HIV became one turning point in a longer story of addiction, despair, and hard-earned progress. Lady E. was able to translate support group perspectives of "living life on life's terms" and "taking control" of one's life circumstances into daily life actions and perceptions of health. However, only four temporarily (un)stable women reported experiencing support groups as positive sources of perspective and/or health-related resources and advice.

Most temporarily (un)stable women found that it was the passing of time gave them a means for re-thinking their ideas about HIV and death. Most women remembered the months following diagnosis as "hell on earth" (Rene) because they feared immediate and painful death. Kareese described her early understandings of HIV infection and how experience over time led her to change her thinking about life with the virus.

At first I was like how are people going to look at me? Am I going to turn gray? Is all my organs going to shut down? At first I was using drugs. I wasn't using no medicine. I had just given up. But I still didn't die. But, I still didn't see that I had another way to think about it. I tried to commit suicide—kill myself twice. But then later, I don't know, I had a change. I had a different look. I wanted to live. I guess I just got to thinking that if I could survive trying to kill myself, I could take the medicine and survive this.

Over time, Kareese's cumulative experiences with HIV health and suicide attempts led her to believe that she could live indefinitely with the virus. Physicians, counselors, and the few support groups she attended soon after diagnosis were unable to convince her that an HIV positive diagnosis did not have to mean certain death. It was time and personal experience that allowed her to dare to envision a future, despite diagnosis with HIV disease. This future necessarily included adherence to medications.

There were many differences in how temporarily (un)stable women came to conceptualize HIV disease as a manageable condition. Despite these differences, the language and perceptual standpoint through which temporarily (un)stable women discussed the experience of HIV disease was consistent. Temporarily (un)stable women discussed the experience of HIV infection in terms of bodily discomfort and blood work

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results. Medication side effects, disease symptoms, and fatigue occupied central

positions in women's descriptions of the lived experiences of HIV/AIDS. Lisa and

Muriel explained what it was like to live with HIV disease in terms of the physical effects

of infection and laboratory analysis of the virus:

> I'm undetectable and my t-cells are up. That's been for a while now. He
> don't even take the blood but a few times a year because I don't go in there
> with complaints. The only thing is that I'm having trouble sleeping. So
> when I go next I'm gonna tell him about it. He'll help me out with that.
> Of course though I may have cervical cancer so I have to go see my
> gynecologist this week too. I had abnormal cells in my pap smear. They
> say HIV can do that. Now that's wild (Lisa).

Lisa explained that she understood her experiences of HIV disease very much in the

terms of medical treatment and disease course. Blood work, illness symptoms, and

fatigue were just a few of the bodily processes that shaped her experiences of disease.

Similarly, Muriel explained life with HIV disease in terms of the physicality of the

experience:

> As the years go by, you wind up taking pill after pill. It takes a toll on you.
> It's when you got nausea, groggy, and sometimes mad. It's feeling groggy
> sometimes. You get hot flashes and sometimes. It [HIV] takes a toll on
> your bones. My skin is dark because there's a blue pill that darkens up my
> skin. It bubbles your blood in your veins and your skin coloration changes
> to dark. Yeah. And sometimes there's this one pill I have to take to harden
> up my stool.

> Later in the interview, Muriel described how she could perceive impending

AIDS-related illness. She said,

> I know when it's mutating—fever chills. That's when you know it's
> mutating. And I try to tell my doctor don't take away the bactrim. That's
> when I need antibiotics is when it's mutating. It pops my ears, I get muscle
> pains and I'm irritable. It's a lot of stuff. You just take it one day at a time.
> It's all you can do. You learn to hear your body. You know when you going
> to get sick.

Muriel's explanation of the lived experience of HIV disease was similar to many

temporarily (un)stable women in that the physicality of infection with the virus was

emphasized over the emotional stress that can sometimes accompany diagnosis. Her

declaration that "you just take it one day at a time" was a common idiom among

temporarily (un)stable women that was used to describe how unstable daily life

conditions could be exacerbated or alleviated in relation to the physical aspects of

infection. For example, despite the fact that Peaches Q. was experiencing a stressful and frightening period of economic uncertainty, she felt optimistic because HIV disease was not yet threatening her physical health.

> I mean I have to be positive, you know. My, uh, CD4 level is way up. Blood pressure is under control. I'm taking my medicine for TB so it's what they call "inactive" now. And, uh, I don't have to take medicine for HIV yet. So I don't have really any worries. I mean I have stress, but as long as I don't get AIDS, I'm doing good.

While Peaches Q. was able to find a source of comfort in her HIV laboratory results despite hardship, other women lamented their laboratory results in light of distress. Dana, for example, was distressed over her lack of social opportunities. Her family lived out of town and only one sibling stayed in touch with her over the telephone. She was recently frightened to hear that her oldest brother learned of her diagnosis as HIV positive and threatened to "come beat [her] ass for getting that shit."

Amidst the fear of being found by her brother, Dana struggled to make ends meet. The chronic stress she faced exacerbated the auditory hallucinations she sometimes heard. To make matters worse, Dana discovered that her home health aid was stealing her prescription pain pills. Dana needed those pills for a recent knee replacement surgery. Her physician refused to prescribe her another re-fill because she had been accused in the past of having an addiction to pain medication. She lamented that the stress of her life was too much considering,

> I have real low t-cells and the other number is way too high. Can't something start going right for me? Nobody to talk to. My family won't even talk to me. No way to get anywhere. No money. And now I'm getting sick? I just feel like sometimes it couldn't get worse. And then it does.

Dana struggled on a daily basis to occupy her thoughts with positive ideas. Social isolation, the physical pain of surgery, and economic hardship were already more than she wanted to cope with. Less than optimal HIV laboratory results became a prism of sorts through which she viewed the other hardships in her life. The immediacy of her multiple needs were brought into focus through her blood work.

Temporarily (un)stable women's perspectives on blood work represented a stark contrast to those of stable women. Consider, for example, how Tamara explained her most recent laboratory results at the time of our second formal interview:

> I can give blood this morning and then go back later on today and they'll
> never be the same. They mean something but it's not really nothing to
> stress out about. It's not exact. If I'm undetectable, it means that there's
> very little copies of the virus in my body. But then again, when I got
> diagnosed, you had to be over 400 or 300 and under to be undetectable.
> Every year they make it different. So even if it [the number of viral copies
> in the body] went up a little bit—say to 175, at one time that was
> undetectable. So why am I stressing? I was undetectable one time because
> I was under 175. You just can't hang on to the numbers too tight because
> they change.

Tamara's understanding of laboratory work as a situational technology led her to think through HIV disease in terms other than CD4 cell counts and viral loads. According to Latour (1979:182), scientific objects, such as laboratory reports, are a means for constructing a reality. The reality of "well-being," as indicated through HIV bloodwork, relies upon viral suppression to the extent that the virus is "undetectable" through diagnostic testing (Rosengarten et al. 2004). However, Tamara questions the viability of viral load testing because the same tests perform differently given such factors as time of day, stress levels, laboratory protocol, and technological developments over time (Corbett 2009). Tamara instead used the perspective and information she learned through the local support group circuit. Support group instructors and "veterans" often instructed women to focus on the emotions they felt concerning their diagnoses. Focusing on the emotions enabled women to control some aspect of their health experience while simultaneously diverting women's attention from test results that were popularly known to fluctuate. With this in mind, Tamara estimated that the realities of HIV infection and health could not be quantified.

Lady E., on the other hand, viewed laboratory analysis as a means of comfort and an indicator of progress with respect to recovering one's health:

> …there's comfort in that [laboratory work]. There's comfort in seeing
> that science work for you. You know? That's the real comfort. Live long,
> be prosperous. Make them labs look good (LadyE).

For temporarily (un)stable women such as Lady E., laboratory results provided a means for measuring "progress" in women's daily lives. As Chapters Five and Six explored, temporarily (un)stable women had difficulty in their efforts to sustain daily life stability or other such improvements in their living conditions. In this context, laboratory analysis

provided a concrete means of tracking one's success in the recovery or maintenance of health.

Temporarily (un)stable women tended to explain their experiences of HIV disease in terms of t-cells, viral loads, and physical effects of infection. Even women who had not recently suffered or perceived any physical symptoms or side-effects of HIV infection or medication explained life in physical terms. Treva, for example, had long ago considered that she would live for a long time. Yet, the *potential* or *typical* physical toll of HIV still provided the language through which she expressed her experiences.

> I'm not like 'oh I'm HIV' you know? I believe god will take care of me. I don't have little routines or anything. I just for the most part try to forget that I'm HIV. It's not too hard to do that when you don't get side effects. I don't get any of that stuff like diarrhea. It's way on the back burner for me. Those medicines make that possible (Treva).

Similarly, Jayla explained that her HIV is not the problem with which she most often deals. She instead must deal with physical discomfort engendered by back surgery and cancer treatment.

> I was told last my t-cells is my viral load is undetectable and my t-cells is up around a thousand. Anyway, it's been undetectable for a long time. My HIV is not the problem. I got more things wrong with me then anyone should be allowed and one of them is not my HIV. I got a hernia and chemo and diabetes and a bad back. They all worse than the HIV (Jayla).

Jayla and Treva both felt that they were in "good health." Despite their favorable laboratory reports, both women continued to explain HIV disease in terms of physical symptoms. For Treva, the lack of symptoms that she considered as typical for an HIV positive person was a comfort. For Jayla, the lack of HIV symptoms was a lens through which she could interpret the severity of other ailments she faced.

Overall, temporarily (un)stable women tended to emphasize the physical aspects of HIV infection. Symptoms, side effects, aches and pains, and other illness experiences provided the perceptual prism through which women made sense of and discussed lived experiences of health. Such perspectives provided temporarily (un)stable women with a concrete language of the virus. This language was applicable to their efforts for medication adherence and treatment success. At the same time, however, perspectives on living with the virus were focused at the individual level. In other words, women had no way to explain poor health outcomes beyond their own perceived failures to abstain from

drug use, adhere to medication regimens, or to exhibit the dietary and exercise habits of a "model patient." Lady E. described that,

> You can only blame yourself if you got AIDS—especially if you use drugs. If your whole main thing is getting away from reality—that's the whole idea so you won't feel, so you won't know, so you won't care. That's on you to care about taking those meds. Let's keep it real. Just call it whatever the hell it really is—"lazy" or "don't give a damn." This is the truth of your life. Take the medication or don't. …they'll know because *they read it [*the truth*] in your blood.*

Lady E.'s declaration that "they [doctors] read the truth in your blood" was more than a statement about how medical and social service professionals estimate whether or not an HIV positive individual is adherent to medications and/or drug cessation programs. "The truth" of which she spoke referred also to the notion that she is partially defined as an individual health outcome in the social fields of biomedicine and federally-funded AIDS care. "The truth" of health relied in this context on individual CD4 cell counts and viral loads. Laboratory analysis, as a health care technology, became the central metaphor through which temporarily (un)stable women understood and perceived HIV disease and their own health trajectories.

Vulnerable Women and Perceptions of HIV Disease

The circumstances of technical and actual homelessness among vulnerable women and their weak connections to the system of care translated into particularly-situated perceptions of HIV disease. Of all the women in this study, vulnerable women tended to have the least obviously medical perceptions of HIV disease and survival. This was due, at least in part, to the reality that vulnerable women attended few events and meetings in the HIV positive community. Lack of attendance at community-sponsored events meant that vulnerable women had fewer opportunities for learning and discussing an emotionally-based or medically-oriented perspective on life with the virus. Lack of attendance at such events was closely related to vulnerable women's strategies for survival.

Because vulnerable women relied so heavily on their personal social networks, disclosure of HIV status was a particularly tricky task that was fraught with uncertainty

and fear. Social researchers have documented the ways in which the stigma of HIV disease permeates the Black community's response to the epidemic (see for example Berger 2004; Cohen 1999; Jones-DeWeever 2005). Stigmatizing discourses and practices surrounding HIV disease were no less apparent in the interpersonal relationships circumscribing women's experiences of survival. Fear of disclosure was a particularly salient issue for vulnerable women because they had few resources other than family members and friends to which they might turn for the satisfaction of basic needs such as food and shelter. Many vulnerable women already lived through several disheartening disclosure experiences with family that left them without crucial resources. Consider for example Chantelle's description of her relationship with her sister:

> How about this here—my sister to a point she's a nurses aid. She a
> CNA. But would you believe she will not let me go upstairs and use
> her bathroom? She say "wait a minute Chantelle. I just cleaned up
> the bathroom, Chantelle." Talking about "I'm cleaning up the bathroom
> Chantelle, you can't use it now." Turn around and say, "you can go use
> it Chantelle. I just clean it up with Clorox when you leave." What
> kind of shit is that? I just walk away. "That's alright, sis." I go right
> around the corner to where her clothes line is, squat, piss, pull my
> clothes up, and go back in her house.

Chantelle was used to using her sister's bathroom as a place where she could shower and use the facilities after a night of sleeping outside. This informal arrangement was made before she disclosed her HIV status to her sister. After disclosure, Chantelle's sister began limiting her use of the bathroom and insisting on washing the facilities with bleach when she did permit her to use them. Chantelle viewed this change in their arrangement as an affront to her dignity. This change also represented a retrenchment of a valuable resource upon which Chantelle had come to rely.

Rachel described a similar story of disclosure that ended in her being denied the support of family members. When Rachel's mother died, she had custody of her four children, two nieces, and one grand niece. She relocated to Indiana at the invitation of her own aunt who had promised to help her raise the children. A week after her arrival in Indiana, Rachel disclosed to her aunt that she was HIV positive. Her aunt's reaction was devastating:

> When I confided in her she went the other way with it. She said that I
> wasn't fit to raise those kids. I needed to give up my rights to them

and give the rights to her because there was no telling how long I would
be around. The youngest one was six at the time, and she was telling me
that there was no way I was going to see him grown and you know this
so face the facts. She just turned on me and made an appointment with
a lawyer.

Rachel was frightened and saddened to hear that her aunt was seeking custody of her children because she was HIV positive. Before official proceedings could occur, Rachel fled her aunt's house with the children in the middle of the night. She left behind all her belongings, including clothing, furniture, and personal items. She and the children made it back to North Carolina with the help of an Indiana Salvation Army program. Although this incident happened more than twelve years ago, Rachel has never fully recovered. At the time of our second interview, she had been actually homeless for more than one year and technically homeless for two years. She was still unable to afford replacement furniture, clothing, and other such items that make an apartment or home habitable. This experience with disclosure left Rachel weary of broaching the subject with other loved ones and friends.

In addition to being directly cut off from the support of family, even strategic disclosure brought with it the potential for breaches of confidence and additional hardship. In most cases, vulnerable women discussed such a dynamic with respect to family members who disclosed a woman's HIV status to friends. Georgia described that,

Like they tell their friends that I'm positive though. That makes me
nervous like what they think about me or who they tell about me. But,
I don't tell my friends because they don't need to know. Like if I tell
my friends or even one of my friends, then I have to fight because they
pick on you.

Georgia found that disclosing her HIV status to relatives meant the likelihood of "accidental" disclosure to friends and acquaintances. This breach of trust translated into a form of extortion engendering social, emotional, and material distress for Georgia. As she explained,

Well like one girl I told and then she told this other girl even though I told her
not to. And then that girl—she would start asking me for stuff like cigarettes
and whatever and when I didn't want to give her none, she called me a "AIDS
carrying bitch." Sometimes if there was people around, I had to give her my
stuff or else then everybody would know. So I stopped telling anybody.
Don't tell just anybody and especially not nobody who will use it over you.

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Georgia's experiences with being intimidated were tinged with regret for every having disclosed her status to individuals she could not, in the end, trust. Being called an "AIDS carrying bitch" was not only an attack on her sense of self-worth. It was also a means of further disclosing Georgia's HIV status to others within earshot of the altercation. This type of disclosure threatened to ostracize Georgia from her personal social network, further complicating her strategies for daily life stability and the satisfaction of basic needs.

Chantelle also had an experience where "unintentional disclosure" left her disconnected from her personal social support network. Chantelle, however, bought her way back into her social circle by providing drugs and alcohol to her friends.

> At first, I wanted to kill myself because everybody knew. And when it get around that 'she has AIDS' and when they seen me coming they shut up. I said "well the only way you going to be my friend is if I buy liquor and crack, and I'll do that." Because I was very lonely even though I'm not alone in this disease, but at the time I felt very lonely, depressed—like I just lost my best friend. You know? It was killing me and I thought why shouldn't I just go ahead and kill myself now. And I was suicidal because I was so depressed and alone.

Despite that Chantelle was able to maintain her social ties to friends by furnishing them with crack and alcohol, she continued to feel isolated and distant from her peers. Chantelle's depression worsened and she soon began devising ways to end her life. In the course of two years, she attempted suicide more than five times. She swallowed large amounts of pills. She jumped in front of cars on the highway. And, she tried night after night to drink herself to death until she achieved temporary sobriety one month before the end of this research. Chantelle's experiences with disclosure had, on all accounts, failed to produce favorable results. She slowly rebuilt her personal social network to include new members who were either unaware of her health status or whom she recognized from Health Partnership and the local health clinic.

The potential for negative experiences informed vulnerable women's decision making about disclosure, even when a particular vulnerable woman had not herself experienced a negative disclosure process. Calculating the potential risks and benefits of HIV disclosure was a serious business that had multiple dimensions with respect to the types of resources women foresaw losing should a disclosure process end unfavorably.

For example, Jamie explained that disclosure represented a potential threat to her efforts at recovery from drug addiction:

> I mean because I can't just call a sponsor or whatever they have at NA because maybe the HIV worries is what's giving me the idea to use. And what if I tell them that and then they're all worried about HIV being contagious. It's just not that easy to find people who can really be trusted with this. I mean there's people you can call at those help lines, but it's different than getting to go and be with someone who will listen and who will hug you and tell you that you can get through it (Jamie).

Jamie worried that disclosing her HIV status to an NA sponsor would lead to discomfort and possibly abandonment during times of need in her recovery process. Conversely, she worried that keeping her HIV status a secret from a recovery sponsor would necessarily mean a lack of communication and honesty between herself and the one person who is meant for her to lean on in times of emotional need. This conundrum could be neither easily nor quickly resolved[xxviii].

The contexts in which vulnerable women perceived HIV disease were personal life contexts shaped by processes of social distress and material deprivation. Social network processes were not easily disentangled from women's material realities because they so heavily relied on family and friends for the satisfaction of basic survival needs. Vulnerable women, like their stable and (un)stable counterparts, perceived meanings and experiences of HIV health in a matrix of over-burdened, fragile, and hostile social networks, social program eligibility restrictions and requirements, and personal life circumstances.

When asked how they would describe what it means to be living with HIV, vulnerable women tended to discuss the virus in terms of the potential and actual effects infection and disclosure have on their social networks and relationships. Tasha, for example, described live with the virus as "hell" because:

> I just think you a outcast. Yeah, I still feel that way. Outcast and especially if somebody finds out. Even my closest friends and the girl that's a female that I felt really close with, I didn't tell her because one day she made a comment like, "I heard she got that shit." She was talking about somebody else. Why would I tell her? You going to think the same thing about me so she don't even know. Yeah, you do feel alone. They say go to like support groups and stuff like that, but trust me you still feel alone. All they do is tell everybody your business.

Tasha explains that HIV disease sets her apart from her peers. The social stigma associated with the virus is acutely felt by women whose lives and livelihoods depend upon peers. While all of the women in this study acknowledged that the stigma of HIV disease partially shaped their disclosure decisions, vulnerable women were the only participants who discussed this stigma as materially and socially devastating. Sharon explained that HIV disease was most burdensome in terms of its affects on her social life. She said,

> The hardest part of living with HIV is like when you meet a nice friend—a male friend and stuff like that. And he's your dream. The person of your dream and then you have to tell him. And then that is your dream and then after you done told him and he don't want you no more.

Tasha and Sharon described how HIV disease affected their social relationships. Friends and family members can unwittingly shape how women experience infection and the virus in their bodies. HIV becomes a social secret of sorts rather than the medical fact explored by temporarily (un)stable women and partially rejected by stable women. The secret of infection was a burden born by all women in this study in at least some situations. However, vulnerable women had perhaps fewer spaces in which to explore HIV disease as a medical phenomenon or process taking place in their bodies because they tended not to frequent educational events, support groups, or other such community forums where medical information can be openly discussed. This was evident when I asked vulnerable women interview questions concerning laboratory work and the biological aspects of infection.

Of all the women in this study, vulnerable women tended to be the least "conversant" with laboratory analyses and medical explanations of HIV disease. In my estimation, this lack of understanding was due to a variety of factors, including their sporadic attendance at physician appointments, poor communication with physicians, and a lack of desire to learn the language of HIV care as taught through service programs. Vulnerable women thus struggled with remembering the terminology for assessing viral progression/regression and the medical interpretation of CD4 cell count and viral load numbers. When asked about their most current laboratory analyses, vulnerable women responded with explanations such as:

I don't know as far as the number wise. I have a appointment next week and

I said that I was going start asking my doctor to help me with it because everybody always asking me (Rachel).

She checked my levels, but I don't really know where they are now. I told her that they probably still aren't all that great. Because they always ask you how many doses have you missed that month. I told her I said and really on the weekends, I really don't [take them]. But Monday through Friday—I usually get up and pop them. But as long as I feel good and I'm taking medicine most of the time, I know that it can't be that bad. (Tasha).

In Tasha and Rachel's estimation, CD4 cell count and viral load numbers fall under the purview of physicians and programmatic services employees. There is perhaps no material advantage for women who understand and use the language of laboratory results. However, it is possible that learning the language of "bloodwork" can provide a social bridge between vulnerable women and care providers who are skeptical of their efforts to comply with institutional norms and guidelines.

Overall, the women in this study brought to bear their daily life circumstances on their perceptions of HIV health outcomes. For stable women, "the truth" to be found in their blood was that laboratory testing was situational and, most importantly, only partially constitutive of the realities of HIV health. Testing sensitivity, timing, and personal health circumstances factored into the numbers they received from physicians. Small drops in CD4 cell counts and incremental rises in viral loads could be seen as a problem of science and technology. This view could be interpreted by service providers as a positive step towards not "using lab work as a lifestyle" (Natasha). In one way, stable women freed themselves from the emotional stress and strain that anxiety concerning laboratory analysis can involve. In another way, stable women firmly entrenched themselves in the individualizing processes of neoliberal policy and ideology.

Temporarily (un)stable and vulnerable women found "the truth" of their blood work to be differently problematic. As the cumulative effects of poverty, addiction, and ill-health translated into difficulties with stress, chemical dependency, and medication adherence, temporarily (un)stable and vulnerable women reported being more likely to miss medication doses or experience a decline in health. Blood work became, in this context, a means for physicians to discern their level of medication adherence. "The truth" of women's commitments to HIV health was discernable through the technology

designed to measure health. Blood work in this way provided a means of surveillance through which particular women could be identified as in need of behavioral intervention.

It is clear that the women in this study differently conceptualized and expressed their feelings concerning the bodily experience HIV infection. While all women had some access to the language of biomedicine via blood work, the relevance of that language was shaped by women's daily life circumstances. Differential use of biomedical language signified the incomplete nature of power in this context. Women consolidated, transformed, and resisted the subjectivity of "potential health outcome" in ways that reflected the social positions from which they engaged with health care and related programs.   Blood work and laboratory analysis became a discourse that illuminated how women could differently use regulatory mechanisms with varied effects on their experiences of health and diagnostic technology.

CHAPTER EIGHT:
RESEARCH FINDINGS AND CLOSING REMARKS

When I returned to the field in May 2009, Kareese's life circumstances had changed only slightly compared to the Monday she was released from short-term psychiatric care. Her strategy of calling upon her institutional network during a period of emotional distress had not unfolded as she had hoped it would. Kareese had struggled for several months to maintain good working relationships with Health Partnership staff members, despite achieving sobriety for several months and talking informally with employees about this achievement. During these months, Kareese complained of poor quality food and service. She refused to attend agency-sponsored substance abuse recovery meetings. She indicated no interest in volunteer work at the organization. At the same time, many of Health Partnership staff assumed that Kareese's decision not to attend agency-sponsored substance abuse meetings meant the she was no longer striving to achieve sobriety. This assumption led staff to follow service provision rules more strictly than they might have had she chosen strategies conversant with behavioral guidelines for service use. Adherence to strict guidelines and rigid protocols provided one means for care providers to protect the organization from federal audits and oversight sanctions.

Under these institutional conditions, Kareese struggled to improve her living conditions. She continued to live with her husband, despite that the two had long ago agreed that their marriage was over. They found a new apartment down the street from where they lived for most of this study. Kareese felt that this apartment was safer than the old one because it was removed from the "no man's land" area between rivaling gangs. This apartment was squarely in a territory controlled by one gang. She no longer feared or "paid mind to" stray bullets as she once had. However, the drug dealers associated with local gangs continued to tempt and lure Kareese into using. She continued to struggle with substance abuse recovery. She also continued to struggle making ends meet each month because she sometimes spent more money than she could spare on illicit drugs.

The escalation in drug use affected Kareese's health, although Kareese felt that the effects were minimal and temporary. Her viral load increased and her CD4 cell count began to decline. Kareese continued to attend physician appointments. She also continued to take her HIV medications most of the time. The health-demoting effects of drug use, however, were becoming apparent. Kareese resolved, once again, to "keep up" with her medications as prescribed. This resolution was in response to recent and discernable changes in her health. For example, Kareese had all of her top teeth pulled shortly before the follow-up phase of the research. Her low CD4 cell count impeded the ability of her gums to heal. She had eaten only soft foods for six weeks when I exited the field in June 2009. As a result, Kareese lost weight and it worried her. The immense hope and determination that Kareese spoke of that Monday in Health Partnership's parking lot dwindled amidst economic worries, escalating chemical dependency issues, and changing health conditions.

It is through the life stories of women like Kareese that I have described how low-income African American women navigate survival with HIV disease in the context of recent Ryan White legislative and institutional changes. The advent of the Ryan White CARE Act in 1990 marked a watershed moment in the management of epidemic disease and the care and support of poor and disenfranchised populations. Local care providers and service recipients recalled a time in which it was easy to give and get the resources needed for daily life stability. Ryan White funds included, for nearly sixteen years, specific and relatively plentiful funds for basic needs such as rental and utilities assistance. The 2006 Treatment Modernization Act, however, dramatically changed the conditions under which HIV positive individuals could access federal support funding and service programs. Despite that North Carolina received more money under the new federal guidelines, new mandates complicated the politics and processes of service provision. Gone were the days of "no questions asked" cash assistance. Gone also were the days of support without health care compliance. Ultimately, the Treatment Modernization Act became a prism through which to view the reproduction and maintenance of social differences among Black women in the interlocking contexts of daily life conditions and institutional support.

The Reproduction and Maintenance of Difference

Although the women in this study were categorically considered as "low-income" within the guidelines of federal and state social service programs, there were significant social and economic differences among them. Most of the women in this study (20 out of 40 participants) endured personal life contexts that were here considered as "temporarily (un)stable." Women in this group tried to meet their basic needs for shelter, food, health care, and income through the use of various programmatic services not under the purview of Ryan White CARE Act legislation. Disability insurance programs, welfare assistance, Medicaid, and public housing programs provided the most readily available access to the means for basic needs satisfaction. Even with their use of such programs and services, women struggled to make ends meet each month. Though technically housed, temporarily (un)stable women tended to live in homes that lacked the features typically associated with quality housing. Women did without such household items as refrigerators, working stoves and ovens, and furniture. In all but one case, temporarily (un)stable women lived in neighborhoods characterized by gang violence and economic blight. A few "temporarily (un)stable women" achieved a kind of transient daily life stability for varying durations of time over the course of the research year. During periods of stability, women were housed in single-family apartment units or homes, their monthly bills were "caught up," and they reported few, if any, difficulties in feeding their families and attending to their HIV health needs. These periods of relative stability were often short-lived, however. Temporarily (un)stable women also experienced varying degrees and bouts of economic decline over the course of the research year. These experiences illustrated how precarious daily life stability can be for women living in poverty. These times of hardship were often mediated by women's personal social network members, if they had any to which they could turn. In many cases, family, friends, and acquaintances were either unable or unwilling to help women solve the problems they faced.

While temporarily (un)stable women simultaneously faced continuous hardship and continuous potential for achieving daily life stability, "vulnerable women" (11 out of 40 participants) enjoyed few opportunities for changing the material conditions of their

daily lives. Women in this group tried to meet their basic needs, to little avail, through the use of state-supported programmatic services such as welfare, vocational rehabilitation, and disability insurance programs. The instability of their daily lives translated into non-compliance with service eligibility criteria. Six vulnerable women did not qualify for disability insurance programs. In addition, a restrictive local job market, chemical dependency issues, criminal conviction records, and illness symptoms impeded women's abilities to secure well-paying, full-time (or even part-time) employment. Without a source of regular income, the women in this group could not afford monthly rental payments.

Five vulnerable women were "technically homeless," meaning they were able to stay indefinitely with family members or friends. In these scenarios, women reported experiencing relative material comfort for as long as their family/friends would allow them to stay. Women living under such circumstances reported exploitative conditions in their host homes. For four vulnerable women, economic deprivation translated into actual homelessness. Their daily lives were largely spent in public spaces such as at the local library, "drop-in centers" for homeless populations, programmatic service offices, and in area parks. As such, they did not have more than a few personal belongings or "conveniences" to which they could turn for material comfort. In either scenario, vulnerable women's most readily available resources were limited to food stamps and personal social networks.

Food stamps were used as a kind of currency through which women could negotiate sleeping on someone's couch, using a friend's kitchen for cooking a hot meal, and/or securing other such basic needs. These informal living arrangements often left women vulnerable to the demands and whims of personal social network members. Vulnerable women thusly faced difficult and chronic conditions of homelessness, physical violence, sexual abuse, periodic bouts of incarceration, and food insecurity.

In contrast to the temporarily (un)stable and vulnerable women in this study, "stable women" (9 out of 40 participants) enjoyed multiple opportunities for creating and sustaining conditions for material comfort and daily life stability. Women included under this categorical umbrella drew from pensions, inheritance, and employment to satisfy basic needs. Stable women supplemented such entitlements and income generation with

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programmatic services such as disability insurance, Section 8, and nutritional support programs such as food stamps. Stable women tended to live in what they described as quality housing in safe and affordable neighborhoods. Although they sometimes reported struggling to pay their bills, women in this group readily acknowledged the comfort they enjoyed as compared to many other women they knew through HIV programs and services.

These economic and material differences among women were partially produced and maintained through the local system of HIV care and related services. These differences resulted from processes associated with federal policy concerning the distribution of resources. Resources were distributed among women in the forms of cash assistance, programmatic services enrollment, and personal favors granted by programmatic service employees. The differential distribution of resources reflects service providers' accountability to funding agencies, federal mandates for care provision, and the broader HIV positive community. Health Partnership would lose its funding in the absence of demonstrable compliance with state mandates and favorable health outcomes resultant from the distribution of organization resources. Nevertheless, participation in HIV-related health programs is here envisioned as a class process that has implications for women's experiences of health and survival.

Federal policy mandates associated with the Treatment Modernization Act operated to restrict access to HIV support services such as emergency cash assistance, case management, nutritional support, and subsidized transportation. Vulnerable women bore the brunt of these policies. At the same time, access to "core medical services" such as treatment adherence counseling, the AIDS Drug Assistance Program, and medical care was expanded. One result of this dynamic was an increased institutional emphasis on "living a life of compliance" with medical needs and behavioral prescriptions concerning health. The health coalition through which I conducted this study served as one nexus wherein the women in this study grappled with and transformed federal policy mandates and the programmatic services through which those mandates are manifest. Given the differences among women in terms of the material conditions of their daily lives, policy mandates and changes to programmatic services protocol were met and negotiated in varied ways. The punitive nature of Treatment Modernization Act guidelines meant that

women had to devise industrious ways to maintain and/or negotiate access to restricted resources. Social network expansion within health care and support institutions was the primary strategy through which women tried to obtain the means for health.

Stable women fared the best in terms of their efforts to expand their social networks to include employees of institutions. First, the beneficial housing conditions stable women enjoyed positioned them well to attend to HIV-related needs. Stable women were most often discussed by service providers as "success stories" because they actively demonstrated their adherence to medications and physician appointments. Their success was also attributable to achieving behavioral goals such as long-term substance abuse recovery, using services "appropriately," and paying their own bills at least most months out of the year. Stable women could be trusted not to "use the system too much" at the same time they could be held up to the public or financial sponsors as proof of service efficacy.

In addition, stable women strategized to maximize their access to resources while simultaneously fulfilling their personal aspirations and goals. Stable women tended to participate in the broader HIV community as "professional volunteers." Their volunteer activities included public speaking, mediating support groups, and participation on Community Advisory Boards. These activities provided women with the opportunity to personalize their relationships with service providers while simultaneously creating a dynamic of reciprocity. In the end, the dynamic that stable women achieved rested on the transformation of institutional networks into personal social networks. This transformation resulted in increased opportunities for cash assistance, participation in special and exclusive programs, and other such forms of "extra" health-related support. Under these conditions, stable women used cash assistance programs as a means for achieving non-health related goals such as for going on modest vacations and for incrementally building savings accounts.

Temporarily (un)stable women did not fare as well as stable women in terms of their abilities to transform institutional relationships into personal social networks. The insecurity of their daily lives and living conditions often translated into missed appointments and non-adherence to medication regimens. In addition, struggles with chemical dependency and chronic mental illness impeded some women's abilities to

conform to the now explicit behavioral guidelines associated with the Ryan White CARE Act. Temporarily (un)stable women were all enrolled in medical care and treatment, but reported at least sometimes missing medication doses and forgetting to update laboratory work. Periodic bouts of instability were also manifest as non-payment of rent and/or utilities several months out of the year. To compensate for their technical "mis-use" of federal funds and programs, temporarily (un)stable women sought to bring health care professionals and service employees into the fold of their daily lives. Women "dropped by" programmatic service offices to chat informally and share the details of their day with employees. They performed volunteer activities at the health organization such as cleaning offices and bathrooms, helping to unload food pantry stock, and organizing the donated wares stored in the client lounge. Their physical and social labor did not tend to result in the expansion of their personal social networks. Rather, they were strengthening their institutional networks. In the absence of relations built on reciprocity, they could not "level" the relationship between themselves and providers of care. Over the course of the research year, no temporarily (un)stable women were able to achieve the long-term stability and social capital enjoyed by stable women. I suspect that, over time, some temporarily (un)stable women will have achieved their goals of daily life stability and health. In the meantime, temporarily (un)stable women continue to rely on programmatic services for support, but have to prove and justify how their needs matter in terms of health. In contrast to their stable counterparts, temporarily (un)stable women continue to be unable to afford "extras" such as savings accounts, new or gently used furniture, social outings, and vacations.

Vulnerable women fare the worst in terms of their abilities to transform institutional relationships into beneficial personal networks. In reality, vulnerable women struggle to create institutional relationships of any material benefit. Ryan White CARE Act guidelines mandate that individuals are not eligible for cash assistance if they cannot substantiate their need for support with a lease or utilities bills in the applicant's name. In cases such as these, women were not given the opportunities they needed to get acquainted with service employees. Women's vulnerabilities to the whims and demands of friends and family members to which they turned for support have sometimes meant increased substance use, sex work, and/or intentional mis-dealings with providers of care.

These coping mechanisms and strategies of survival are ultimately harmful to vulnerable women because they render them as "unreachable" to service providers accountable to oversight mandates. Thus in other cases, vulnerable women are ill-positioned to meet the service provision demands of "appropriate" service use and/or the behavioral criteria for assistance. Vulnerable women who volunteered their labor at the organization were often understood as trying to secure extra food pantry items rather than acting for the good of the community.

The Implications of Differences for Perceptions of Survival With HIV Disease

It was through the dynamics between programmatic services and daily life conditions that the women in this study perceived treatment for and survival with HIV disease. The extent to which women participated in health coalition programs shaped their abilities to access means to health such as quality housing, food, medication, and income support. Access to resources for health was partially dependent upon women's abilities to convey their conformity with medical logic and health-related behavioral proscriptions. Health coalition programs sought to instill medical logic in women's perceptions of survival with HIV disease through education about CD4 cell counts, viral loads, and basic knowledge concerning the HIV disease course. Women's use of such logic, coupled with living conditions and health needs, shaped how they perceived their health.

Stable women tended to most often discuss HIV disease as a minor inconvenience in their lives. Their participation in support groups, community events, and personalized institutional social networks gave them ample opportunities for discussing HIV disease and adopting philosophies of survival sanctioned by health coalition programs. In addition, their relatively advantageous positioning with respect to affordable and safe housing and income assistance translated into optimistic understandings of HIV disease and the potential trajectories of their health. In all cases among stable women, HIV disease was described as an "emotional journey" over which individual women could take control by employing medical tactics such as treatment adherence and stress reduction. Sustained focus on the emotional dimensions of HIV infection were partially

engendered by women's understandings of laboratory analysis as a "situational technology" that is incapable of explaining the realities of health. Rather, stable women explained that laboratory tests can only find the presence or absence of disease in the human body at any given point in time. New developments in testing technologies render laboratory results as markers of disease rather than indicators of well-being or longevity.

A few temporarily (un)stable women described how HIV disease was a new found means for changing the conditions of their lives. Viral infection was explained as a "catalyst" for life changes such as cessation of drug use. Women who felt this way tended to have made self-defined progress in their attempts to improve living conditions, health needs, and social circumstances. They were stable for at least the short-term future. In contrast, most temporarily (un)stable women described how it was the laboratory analyses and medical care that gave them a means for re-thinking their ideas about HIV and death. The tracking of adherence to medications through "blood work" provided women with a means for measuring "progress" made through health care participation. Women in this group thus described their perceptions of HIV disease in terms of viral loads, CD4 cells, and the physical side-effects associated with infection and treatment.

Vulnerable women tended to have the least obviously medical perceptions of HIV disease. This was due, at least in part, to the reality that vulnerable women attended few events and meetings in the HIV positive community. Lack of attendance at community-sponsored events meant that vulnerable women had fewer opportunities for learning and discussing an emotionally-based or medically-oriented perspective on life with the virus. This lack of opportunity and participation was closely related to vulnerable women's need for reliance upon family members and friends. Disclosure of health status to friends and family represented a potential threat to women's efforts to secure resources. HIV disease, in this context, was perceived and discussed by women as a social condition representing imminent threat to safety and well-being.

Theoretical Contributions to Anthropology

Understanding women's lived experiences of HIV disease in relation to broader structural conditions yields two theoretical contributions to the anthropological literature concerning health. Perhaps first and foremost, anthropologists have long been concerned with the ways in which conditions and distributions of health and illness are structured by social change, power relations, and lived experiences of inequality (Breen 2002; Inhorn 1995). The HIV/AIDS epidemic has proven fertile ground for discerning the social mechanisms by which disease is distributed along axes of inequality (see for example Collins 2001; Farmer et al. 1996; Pivnick 1993; Schneider and Stoller 1995; Singer 1991). Social researchers have also used the HIV/AIDS epidemic as a lens onto inequalities in access to health care and political power (see for example Berger 2004; Cohen 1999; Maskovsky 2000; Rodriguez-Trias and Marte 1996; Rylko-Bauer and Farmer 2002). Such studies have provided invaluable insights into the ways in which macro-level policies and procedures shape local conditions of health and health care. What has been less well explored in the context of HIV/AIDS, however, are the ways in which local social actors transform, consolidate, and resist these broader structures of inequity that shape chances for health.

By exploring Midway's system of care as a social process, rather than as a series of policies and programs, this research illuminates the ways in which "state level" public health care services are shaped by local social actors. Viewing federal legislation from the ground up, so to speak, opens up the theoretical space necessary for better understanding the dynamics among autonomy, agency, and constraint under varying conditions of health and economics. As I illuminate throughout the dissertation, health is neither fully constituted by macro-level structural constraints nor can conditions of health be reducible to biomedical interpretations of individual pathology. Rather, this research makes clear the ways in which experiences and conditions of health constitute and are constituted by a fluid and dynamic social terrain. This standpoint necessarily emphasizes the social, political, and historical specificity of health, illness, and healing. HIV/AIDS here provided one lens during a particular moment in time through which to understand

the social and institutional processes circumscribing survival with a chronic and infectious disease.

In a related line of thought, this research also contributes to Black feminist literature concerned with validating Black women's lived experiences as a fruitful site for the production of new concepts, theories, and ideas. The examination of Black women's lived experiences of HIV disease in the contexts of neighborhood, home, and social service institutions spotlights the incomplete and contingent nature of power in the current neoliberal context. Women variably used and resisted neoliberal ideals of self-management and personal responsibility according to their social positions within the local system of care. By positioning AIDS care and support services within the broader contexts of neoliberal economics and ideology, Black women's service utilization tactics became intelligible as sophisticated strategies for health, daily life stability, and socioeconomic advancement. I call the culmination of these tactics "social network surrogacy." Conceptualizing women's service use in this way provides a means to squarely position institutional processes within the intimate terrains of daily life and perceptions of health. It is through women's lived experiences of and strategies for social network surrogacy in this context that the relationships among health, health care policy and provision, and neoliberal economics can be called into question. As such, the social network processes and survival experiences highlighted here provide an entry point for thinking through public health care and related support services as social processes that structure and are structured by capitalism.

Lessons From Midway

At a most basic level, the varied experiences of HIV positive women in Midway point to the need for flexibility in HIV-related social programs and service delivery designs. The considerable social and economic differences among women consistently affected study participants' abilities to attend to their health and related needs. In my estimation, Health Partnership staff could address these differences as a part of their efforts to provide optimal care under less than optimal policy conditions. At the time of this research, differences among women tended to be discussed by providers in terms of

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their perceptions concerning women's commitments to self-reliance, health, and the broader HIV positive community. Therapeutic goals of substance abuse recovery and HIV health coupled with social work goals of personal responsibility and empowerment provided an important part of the backdrop against which staff implemented federal policy mandates. This meant that women's actions were interpreted by care providers in absolute terms of compliance or non-compliance with behavioral prescriptions concerning health.

For the women in this study, the reality was that there were varying degrees of compliance with behavioral and therapeutic goals. Even stable women who utilized bureaucratic strategies as a means for achieving socioeconomic stability and advancement sometimes "bent the rules" for economic gain. However, when interpreted as strategies for investing in a future independent of Health Partnership, their actions become intelligible as using a viable social network to secure future economic stability. As sometimes "hard to reach" or "self-destructive" clients, temporarily (un)stable and vulnerable women were rarely understood as having future plans for stability that did not include assistance from Health Partnership. This was in part because Health Partnership staff recognized the fragility that characterized many women's personal networks. They did not, however, recognize themselves as existing in the constrained networks cultivated by women. This meant that employees envisioned programmatic service use as a temporary fix for economic and/or behavioral problems rather than as a social process reflective of the articulations between historically-based inequality and contemporary policy provisions.

Because Health Partnership represented an important link in women's social networks, it serves as an entry point for creating a "community" or communities of women based around shared goals as determined by the group(s). For some women, their health care needs remain basic. Food, housing, access to medications, substance abuse cessation, and income represent their greatest obstacles to realizing stability and health. For other women, their needs include support in finding gainful employment, a social outlet, and/or continued emotional support. Still other women desire socioeconomic advancement, but are well-positioned to care for themselves and their loved ones. These group level distinctions can provide a starting point for discussing the varied needs of

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HIV positive women and the short-comings of current policy and programmatic approaches to meeting those varied needs. Health Partnership, as an organizing entity in women's daily lives, can facilitate women's participation in defining a broader continuum of community goals and values by providing a venue and the impetus for the formation of action-oriented groups. The facilitation of such groups could ultimately strengthen women's social networks by encouraging collaboration among women who otherwise would not work together. In turn, the facilitation of action-group(s) of women could bolster the survivability of Health Partnership through advocacy and lobbying efforts aimed at attending to the structural conditions shaping survival with HIV disease.

End Notes

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[i] To protect their privacy, each research participant chose or was assigned a pseudonym.

[ii] Midway and Health Partnership are pseudonyms. I originally planned not to disclose the city or the state where this research was conducted. After talking with research participants and the executive director of the organization, I settled on disclosing the state only. Health Partnership's executive director was comfortable with publicly naming both the location of the research and the organization's real name. She discussed this comfort in terms of confidence in the organization's services, protocol, and staff. The women about whom this dissertation is written were not comfortable with disclosure. They preferred to keep the city and organization name private.

[iii] The Treatment Modernization Act (TMA) amends and re-authorizes the Ryan White CARE Act from 2006-2009. In general, the guidelines serve to re-prioritize funding levels for different states. States in the US South received significantly more federal dollars than they had in years past. North Carolina, in particular, received a 6.5 million dollar increase in funding for the fiscal year 2007.

Funding level increases for southern states ushered in new regulations about how Ryan White money can be spent. In the South, adding new programs for substance abuse recovery, behavioral interventions, and medical care were a priority. In fact, 75% of all Ryan White funds were specifically targeted to core medical services, including physician appointments, prescription programs, and medical adherence counseling. While legislation stipulated that money should be used to build such medically-oriented programs and capacity, definitions of how these programs should operate were left unaddressed. Service providers created and implemented their own programs in response to local conditions. The problem, however, was that care providers faced being told "after the fact" that they could not be reimbursed by Ryan White funds for particular types of services because they were deemed as non-compliant with federal regulations. As a result, the first four or five months of this research bore witness to a time of immense change and programmatic uncertainty.

[iv] Black feminism represents an intellectual project aimed at challenging structures of domination that circumscribe the lives of African-descended people. This includes understanding the roles that masculinist forms of academic research and its associated practices have played in the subjugation of people of color (Bolles 2001:29). In anthropology, Black feminism is committed to exploring the ways in which the politics of race, class, and gender inform ethnographic practice. Turning the analytical gaze onto anthropological theory and method, the Black feminist intellectual tradition implicates academic practice in the production and maintenance of social difference. Basic concepts such as gender, identity, and health have been re-worked by Black feminist theorists who seek to establish an anthropological perspective grounded in experiential knowledge.

[v] Health Partnership was established in 1999. The agency represents the consolidation of three agencies, each of which had been serving area clients since the first Ryan White funds became available in 1992. In 1996, local agency representatives began talking about the prospect of consolidation for financial reasons. By 1999, the three agencies

united to provide faith ministries, counseling, and financial assistance to HIV positive residents.

vi The North Carolina HIV/AIDS consortium serves as an inter-mediary between HIV service organizations, the state of North Carolina, and the federal government. All billing is submitted to the Consortium for reimbursement. Oversight mandates and quality assurance techniques are carried out by the Consortium. However, the Treatment Modernization Act re-defined state billing consortiums as being "support services." The result is that operating costs for the consortium are drawn from the 25 percent funding umbrella for support services. To save money for the direct provision of support services, North Carolina is dismantling the consortium. Agencies will begin contracting directly with the state over the next two years.

vii CD4 cells are a type of white blood cell, also known as a t-cell. The cells that HIV infects are most often CD4 cells. With HIV infection, the DNA of the virus becomes part of the CD4 cell. Paradoxically, when CD4 cells multiply as an immune response to the infection, they also make more replications of the virus. As the virus progresses, the body makes fewer CD4 cells while copies of the virus proliferate. A person with fewer than 200 CD4 cells is considered to have AIDS (CDC 1992). A viral load test measures the amount of HIV virus in the blood. Currently, tests can detect anywhere from 5 copies to one million copies per milliliter of blood. Viral load testing along with CD4 cell count testing can provide insight as to the efficacy of drug treatments and disease course (Peter and Sevall 2004).

viii When I returned to the field in May 2009, the new fiscal year had just started for Ryan White programs. The new fiscal year ushered in an important change for the provision of emergency assistance programs. Under the new federal guideline, HIV support service clients are eligible for a maximum of 21 weeks of emergency financial support. For example, if Health Partnership paid a client's rent one month, then that was considered four weeks of support. This change was the first time that formal and federally-mandated restrictions had been placed on emergency financial assistance at Health Partnership.

ix When I returned for follow-up activities, Health Partnership had already begun to participate in another federal program for nutritional assistance, The Emergency Food Assistance Program (TEFAP). Health Partnership received monthly deliveries of food, fresh, frozen, and canned. Recipients had to qualify for the "extra" food by proving their financial need. Recipients had to receive or at least qualify for food stamps. Not all clients at Health Partnership could prove this need, despite their regular participation in Health Partnership assistance programs and food pantry services.

x SSDI and SSI both provide monthly benefits checks for disabled persons living with HIV/AIDS. Persons who have worked in the preceding ten years and have paid Social Security taxes are eligible for SSDI. Persons who do not have a consistent work history or who have not paid Social Security taxes are eligible for SSI. In some cases where an individual has very few resources and a history of consistently very low-income

employment, they may receive benefits from both programs (Social Security Administration 2009).

[xi] Disabilities benefits recipients can earn up to $979 per month in additional income. Anyone earning $980 or more per month is considered able to participate in "substantial gainful activity" (Social Security Administration 2009).

[xii] North Carolina food stamp benefits calculations are officially based on monthly income and household size. For a single woman with no children, the monthly income limit is $1,127. A woman who receives $1,127 each month in income technically qualifies for $176 in food stamps (North Carolina Division of Social Services 2009). However, many women reported incomes far below the monthly limit and still received less than the maximum benefit allotment. This situation could be the result of inaccurate paperwork on the part of social service employees or inaccurate income reporting on the part of study participants. In some cases, women explained that rent and utilities subsidies affect benefits calculations. In other cases, women are unsure as to why they do not receive more food stamps than they do.

[xiii] Women often recalled the days when they could buy a small, inexpensive item such as a soda and pay for it with food stamps. They would then receive cash back as change for the food stamp. This strategy was discussed as an important way for women to purchase household necessities, such as soap and toilet paper, that are not considered as food items by Food and Nutritional Services.

[xiv] Health Partnership employees often struggled with the idea of fee-for-service case management. On one hand, it provided a means of bringing more income into the organization. Since case manager salaries are paid through United Way funds and Ryan White funds, Medicaid billing money would essentially represent cash flow in the broader organization. Cash flow allows employees to "spend down" their budgets more effectively because they can wait longer to be reimbursed by the Consortium. They would also have more disposable monies for agency-sponsored programs and events.

On the other hand, case managers worried that entering into the fee-for-service case management arrangement would cause commotion in the broader community. Employees worry that other organizations would resent Health Partnership because they already receive the "lion's share" of Ryan White Part B funds in the community. In addition, employees worried that clients would expect them to expand the boundaries of their services to informally include transportation.

[xv] Feminist researchers have developed a literature of methodological reflexivity that is based in understanding the politics of conducting research. Questions of rapport building, the dialectical potential of interview formats (Rheinharz 1992), and representation are key subjects in this literature. An explicit concern with "difference" underlies all of these subjects and scholarly writings about performing social research. Martin (1994), for example, points out that the feminist denial of essential womanhood has led to a number of "methodological traps." In particular, Martin (1994:637) asserts

that the focus on difference *between* groups of women has led to a form of essentialism. She argues that it was indeed methodologically and epistemologically necessary to acknowledge the considerable diversity among women. That diversity, however, tends to be used by researchers in ways that essentialize groups of women on the basis of one characteristic, such as race or nationality. With these critiques in mind, I designed this research to explore the differences among African American women living with HIV.

[xvi] Surplus value is here defined as the increase in the value of capital following investment in production (Marx 1972:351).

[xvii] "Healthy housing" was a phrase often used by service providers at Health Partnership. In general, the organization maintains an official stance that housing is a health care need. Although recent changes in Ryan White funding contracts do not consider housing as a "core medical need," lobbyists on behalf of Health Partnership hope to change that definition within future legislation. Because "healthy housing" is not a legislative priority, it has no formal definition. However, service providers talk about healthy housing in terms of a lack of pests and mold, working utilities and appliances, safe neighborhoods that are free of violence and drug activity, and clean carpets and restroom facilities.

[xviii] Boosting is when a person steals items from businesses and/or homes and then sells them.

[xix] When I returned to the field in May 2099, Tasha was still/again technically homeless. She and her renewed acquaintance from the shelter had lived together for almost two months. Tasha explained to me that the house they moved into was in a neighborhood where it was easy to get drugs. Both women began to use crack regularly. The house soon became "a party house" where friends would come to smoke, share, and/or buy crack. After a brief while, Tasha left the house. Her probation officer told her that if she was caught doing drugs or was arrested for any charges, she would be incarcerated again. At the time of our follow-up interview, Tasha was temporarily staying with a friend while she tried for enrollment in a long-term recovery house for women.

[xx] Community Advisory Boards come out of the AIDS Clinical Trials Groups of the 1980s who advocated for broader inclusion and expedient processing and dissemination of clinical trials information and results. The current form, community advisory boards, emerged in the early 1990s. CAB members tend to be non-scientists who might represent a range of community interests such as schools, religious groups and/or community based organizations. CABs currently operate to conduct outreach, review and evaluate clinical trials protocol, and facilitate productive relationships between researchers and the broader communities in which they work (International AIDS Vaccine Initiative 2009).

[xxi] According to the guest speaker, in August 2007, Selezentry was approved as an "entry inhibitor." Essentially, entry inhibitors prevent the HIV virus from attaching to otherwise healthy cells (Briz 2006; Dolin 2008; Este and Telenti 2007). Isentress was approved in October 2007 and is an integrase inhibitor. Integrase inhibitors prevent the HIV virus

from attaching to DNA molecules once the virus has entered the cell (Evering and Markowitz 2008; Havlir 2008). Finally, Intelence was approved in January 2008. Intelence is a non-nucleotide reverse transcriptase inhibitor (NNRTI). NNRTIs prevent HIV replication in the body (DiNubile 2008).

xxii "Those things we can control" is a reference to the serenity prayer that is often used in at meetings for Alcoholics Anonymous and Narcotics Anonymous. Although Health Partnership is an organization that uses a type of harm reduction to guide therapeutic policies and programs, they do incorporate aspects of other faith-based recovery programs, such as the "serenity prayer," that program enrollees find useful.

xxiii A key part of the Treatment Modernization Act includes tightening restrictions on how funding can be spent and increased reporting requirements. Each dollar that passed through Health Partnership was tracked and recorded by several people. Administrative staff, counselors, and officials from the state's HIV care consortium all had a vested interested in recording how much money was spent, on whom, and for what reason. In cases where Health Partnership could not document or did not properly document the disbursement of Ryan White funds to a client, the funds were not reimbursed by care consortium. Health Partnership "lost" that money unless they could find the correct documentation and submit the necessary paperwork before the quarter deadline.

xxiv The Black Church Week of Prayer is held every year nationally and in Midway. The goal is to include area churches in the dialogue concerning the HIV epidemic. It is a week of support, education, and community involvement. HIV/AIDS is still heavily stigmatized in Midway. The stigmatization of HIV disease often means that women's illness experiences and needs are little discussed as a part of a "Black mainstream" political, social, and/or economic agenda (Cohen 1999). HIV disease is thus still often regarded by institutions in the Black community as a disease of the "other" or "undeserving" (Berger 2004; Jones-DeWeever 2005). This week marks for some women one of the few moments when their church congregations will acknowledge the epidemic and the struggles of persons living with HIV.

xxv Agency-wide spend downs occurred twice during the research year. A "spend down" is part of budget realignment, or the process of spending federal funds to match the projected budgets submitted to the federal government. Budget realignment happens when the agency has not spent all of the money to which they are entitled. If they do not spend the money, they will receive less funding the following year. Periodically, the state HIV/AIDS consortium will advise agencies to "spend down" their funds so that the proposed budgets match the actual amount of money spent on services and programs.

xxvi "Citizenry" in this context refers to the self-reflexive subjects constructed through an individual's conformance to state policies and practices.

xxvii At their discretion, states can mandate that organizations receiving federal and state funds use standardized software for reporting HIV health outcomes. In North Carolina, any agency receiving federal funds for prevention are required to use CAREWare

software. Health Partnership employees were trained on this software during the research year and underwent the tedious task of converting all client files in the electronic database. The database is a shared system that connected hospitals and AIDS service organizations to facilitate information sharing. Information sharing was imagined to increase the quality of care provided to individual clients by making sure that each provider knew "the whole story" of their living conditions and health needs. Health Partnership was aware of the potential problems they faced in terms of confidentiality and client trust. They opted to mandate that their own substance abuse counselor keep separate files on chemical dependency cases. The substance abuse counselor recorded if a client came to see her into CAREWare, but did not enter any other information into the system. Similarly, the CRCS counselor was not mandated to share client information over CAREWare. Issues concerning medication adherence, nutrition, and emergency assistance were included in the shared files digital folder, however.

[xxviii] I never discussed this issue with counselors from Narcotics Anonymous or Alcoholics Anonymous. It is quite possible that there are strategies in place for matching HIV positive "sponsees" with sponsors who are comfortable working with HIV positive individuals. However, women would have to trust a support group organizer enough to disclose her HIV status in that context before any accommodations could be made.

Appendix 1: Demographic Characteristics of Study Participants

	Monthly income	Major Income Sources	Housing Status/ payment	Substance use status	Marital Status	Education	Year of HIV diagnosis	Age
Lady E.	$250 until SSDI ($650)	Small business/ welfare until SSDI approved	Renter/ $435 per month	In recovery	Never married	College degree	1993	49
Peaches Q.	$900	SSDI of husband/ employment	Renter/ $300	Never used drugs	Married	12th (no diploma)	2005	50
Christina	$860 - $875	SSDI/ odd jobs	Renter/ $475	In recovery	Never married	11th grade	2001	33
DeeDee	$1400	Military pension/ temporary work	Cares for mother in family home/ approx. $200	In recovery	Never Married	Some college	1999	48
Lisa	$723	SSD/ stipend for non-profit work	Renter/ $475	Intermittent recovery/ active addiction	Never married	Some college	1993	50
Donna	$416	Part-time CNA work	Technical homeless	Declined to discuss	Never married	10th grade	1999	49
Chantelle	$0	No source of cash income	Actual homeless	Active addiction	Widowed	GED	2000	45
Debdai	$600	SSDI/ survivor's benefits	Renter/ $82	Never used drugs	Never married	High school diploma	2000	45
Tamara	Declined to be specific. Finances indicated as "middle class"	Husband's income	Home owner/ payment not specified	Never used drugs	married	High school diploma	2004	42
Sharon	$500	SSDI	Technical homeless/ $250	Active addiction	Divorced	10th grade	1999	45
Lessa	$636	SSDI	Renter/ $325	Active addiction	Separated	10th grade	2000	52
Tasha	$900	Disability	Actual homeless	Active addiction	Never married	Diploma	1996	47
Andrea	$0	None	Renter/ $0 family	Declined to discuss	Never married	9th grade	2000	45
Treva	$620	SSDI	Renter/ $450	In recovery	Married	11th grade	1990	47
Stacey	$637	SSI	Renter/ $0 through program	In recovery	Never married	Associates degree	1991	50
Elizabeth	$1000	Odd jobs/spouse	Renter/ $425	Active addiction	Married	High school diploma	1997	42
Charlotte	$950	SSI/SSDI	Renter/ $140	Long-term recovery	Divorced	Some college	1999	51
Kareese	$745	SSDI	Renter/ $325 split with husband	In recovery	Married	10th grade	2000	37
Marjorie	$200-$900	Temporary work	Renter/ $150	Never used drugs	Never married	High school diploma	2002	32
Danielle	$657	SSDI	Renter/ $161	Never used drugs	Divorced	11th grade	Early 1990s	68

Tanya	$100 until employed $930	employment	Renter/ $0 until employed $425	Never used drugs	Married	High school diploma	Early 2000s	26
Joan	$950	SSDI and SSI	Renter/ $120	Never used drugs	Married	Some college	1993	33
Dana	$637	SSDI	Renter/ $320	In recovery	Never married	7th grade	Early 1990s	
Linda	$900 -1725	employment / survivor's benefits	Renter/ $850	Never used drugs	Widowed	Some college	1998	forties
Rene	$600	SSDI	Renter/ $127	Long-term recovery	Never married	4th grade	1990	59
Ashley	$1400	SSI/ employment	Renter/ $300	Never used drugs	Never married	11th grade	2000	Upper fifties
Georgia	$30 - $40	Odd jobs	Technical homeless	Active addiction	Never married	11th grade	1998	44
Muriel	$546	Disability	Renter/ $127	Active addiction	Never married	11th grade	1987	45
Rosalind	$0		Technical homeless	Never used drugs	Never married	High school diploma	2006	53
Jayla	$637	SSDI	Renter/ $250	Never used drugs	Separated	High school diploma	1991	50
Grace	Approximated $1400	SSDI and pension	Renter/ $630	Never used drugs	divorced	Bachelor's degree	2004	51
Raquel	$645	SSDI	Renter/ $375	Active addiction	Never married	7th grade	Unsure, more than 10 years ago	47
Brenda	$1452	SSI and survivor's benefits	Renter/ $580	Never used drugs	Never married	11th grade	2006	34
Samantha	$694	SSDI	Renter/ $550	Active addiction	Married	10th grade	1993	43
Rachel	$563	SSDI	Actual homeless	In recovery	Never married	10th grade	1995	Early fifties
Shayna	$656	SSDI	Renter/ $375	In recovery	Never married	11th grade	Early 1990s	51
Amanda	$0		Recovery house/ $0	In recovery	Separated	GED	2007	42
Karen	$643	SSDI and SSI	Renter/ $52	In recovery	Never married	High school diploma	1985	48
Jamie	$0		Technical homeless	Trying for recovery	Divorced/widowed	High school diploma	2000	43
Noelle	$726	SSI and VA pension	Renter/ $350	In recovery	widowed	11th grade	1994	42

Appendix 2: Study Participants' Analytic Categories

Stable Women	Monthly Income	Rent as % of income	"Disposable" Income (average basic home bills $241)
DeeDee	$1400	14%	$963
Debdai	$600	14%	$275
Tamara	Not specified	Not specified	Not available
Stacey	$637	0	$396
Charlotte	$950	14%	$576
Danielle	$657	24%	$259.76
Joan	$950	12%	$595
Ashley	$1400	7%	$1061
Grace (payee)	$1400	45%	$529

Momentarily (un)stable Women	Monthly Income	Rent As % of Income / Lease in name?	"Disposable" Income (average basic home bills $241)
Lady E.	$800	54%	$124
Peaches Q.	$900	33%	$359
Christina	$875	54%	$159
Lisa	$723	65%	$7
Lessa	$636 (payee)	51%	$70
Treva	$620	72%	-$71
Kareese	$745	43%	$179
Marjorie	$900 (variable)	16%	$750
Tanya	$930	45%	$264
Dana	$637	50%	$317
Rene	$600	21%	$232
Muriel	$546	23%	$178
Jayla	$637	39%	$146
Samantha	$694	79%	-$97
Shayna	$656	57%	$40
Karen	$643	8%	$350
Noelle	$726	48%	$135
Brenda	$1452	39%	$631
Linda	$1725	49%	$634
Raquel	$645 (payee)	58%	$29

Vulnerable Women	Monthly Income	Rent as a Percent of Income	"Disposable" Income (average basic home bills $241)
Donna	$416 (until job lost)	Technical homeless/ no rent	Any cash earned goes to utilities
Chantelle	$0	Actual Homeless	Any cash earned goes to potential host
Sharon	$500	Technical homeless/ 50% goes to brother	Extra cash goes to host for utilities and food
Tasha	$900	Actual homeless	Extra cash goes to potential host, hotel rooms
Andrea	$0	Family pays rent temporarily	No cash
Elizabeth	$1000 (variable spousal income)	45%	$309 (controlled by spouse)

Georgia	$40	Technical homeless	Cash goes to household
Rosalind	$0	Technical homeless	$0
Rachel	$563	Actual homeless	$563
Amanda	$0	Recovery house	$0
Jamie	$0	Technical homeless, though secure in relationship	$0

Appendix 3: Glossary of Service Program Acronyms (in alphabetical order)

ADAP (AIDS Drug Assistance Program): The North Carolina AIDS Drug Assistance Program uses a combination of State and federal funds to provide low-income residents with access to HIV/AIDS medications, including medications desgined to treat the opportunistic infections associated with the virus (USDHHS 2009c).

AFDC (AID to Families with Dependent Children): AFDC was a federal income assistance program for children and the families of unemployed parents. The program was originally outlined in Title IV of the 1935 Social Security Act. It remained in existence until 1995 when it was dismantled as a part of the 1996 welfare reform efforts of the Clinton era (USDHHS 2009b).

CRCS (Comprehensive Risk Counseling and Services): CRCS is a federally funded program designed to be an intensive, individual-level risk reduction and intervention service. Program participants meet with a risk reduction counselor for individual consultations and counseling sessions. The primary goal of the service is to reduce the chances of HIV infection and transmission among individuals who are considered to be at high risk. The program was formerly known as "prevention case management" (Centers for Disease Control 2009).

EBT (Electronic Benefits Transfer): EBT refers to the state nutritional assistance program, also known as food stamps. Participants receive a plastic card, much like a credit card, onto which their "food stamp money" is deposited each month (North Carolina DHHS 2009).

FEMA (Federal Emergency Management Agency): FEMA is a federal agency charged with the task of mitigating disaster and coordinating recovery programs associated with disaster. FEMA created the Emergency Food and Shelter National Board Program in 1983 to supplement the work of local social service organizations in the United States. This program provides food and money, allocated by states, for the support of homeless and food insecure populations (US Federal Emergency Management Agency 2009).

HOPWA (Housing Opportunities for People with AIDS): HOPWA is a federal program that provides grants to states and cities for a variety of services, including housing assistance for HIV positive populations. The funds can be used for the acquisition, rehabilitation, or new construction of housing units; costs for housing facility operations; rental assistance for individuals living with HIV/AIDS; and short-term payments to prevent homelessness (US Department of Housing and Urban Development 2009).

PRWORA (Personal Responsibility and Work Opportunity Reconciliation Act):
PRWORA is a comprehensive welfare reform bill that congress enacted in 1997. Essentially, the bill dismantled AFDC and replaced it with Temporary Assistance for

Needy Families. The broader bill contains work requirements that mandate welfare recipients to work in exchange for their benefits after two years of enrollment, with a lifetime limit of benefits receipt equal to 5 years. The bill also provides performance bonuses to reward states for moving welfare recipients into paid jobs. PWORA also stipulates additional child care funding for eligible families and health care coverage for recipients, including one year of Medicaid coverage when participants leave welfare for work.

In addition, PWORA includes for comprehensive child support enforcement, including an executive action to track "delinquent parents" across state lines. The law expanded wage garnishment, allowed states to seize assets and require community service, and to revoke drivers' licenses from parents who owe delinquent child support (USDHHS 2009a).

Ryan White CARE Act (Ryan White Comprehensive AIDS Resources Emergency Act): The Ryan White CARE Act was first authorized in 1990. The act provides the impetus for federal support of HIV/AIDS health care and related programs. The Ryan White program works with cities, states, and local community-based organizations to provide services for HIV positive individuals who do not have sufficient health care coverage or financial resources for managing the disease (USDHHS 2009c).

SNAP (State Nutritional Assistance Program):   Since 1997, SNAP has provided funds for North Carolina central food distribution centers. The central distribution centers use the funds to purchase staple foods in bulk from North Carolina companies. In turn, these staple foods are distributed to area food banks, rescue missions, soup kitchens, and various types of publically-funded shelters (Food Bank of Central and Eastern North Carolina 2009).

SSDI (Social Security Disability Insurance): SSDI is a federal program for people with disabilities who are unable to work. The program pays benefits to individuals who have a qualifying disability and who have paid a qualifying amount in Social Security taxes. Qualifying disabilities include medical conditions that result in the inability to perform work and/or that are expected to last at least one year or result in death. Individuals accumulate Social Security work credits based on total yearly wages, with a maximum of 4 credits earned each year (equivalent to earning $4,480). Individuals who have accumulated 40 credits, 20 of which were earned in the ten years prior to the onset of the disability, qualify for the program (Social Security Administration 2009).

SSI (Supplemental Security Insurance): SSI is a federal income support program that is funded by general taxes (not Social Security). Disabled individuals who have limited income and resources can qualify for this program. Payments are based on financial need. SSDI payments are included as a resource in SSI eligibility calculations (Social Security Administration 2009).

TANF (Temporary Assistance for Needy Families): Under the welfare reform legislation of 1996, (PWRORA), TANF replaced the welfare programs known as Aid to Families with Dependent Children (AFDC), the Job Opportunities and Basic Skills

Training (JOBS) program and the Emergency Assistance (EA) program. The law ended federal entitlement to assistance and instead created TANF as a block grant that provides States, territories and tribes federal funds each year. These funds cover benefits, administrative expenses, and services targeted to poor families (USDHHS 2009d).

TEFAP (The Emergency Food Assistance Program):   Under 1996 Welfare Reform, TEFAP and the Soup Kitchen/USDA Commodities have been merged into one program. TEFAP is administered by the the state. Funds are used to purchase food for low-income populations. The food is distributed through emergency assistance agencies and other charities for registered clients (Food Bank of Central and Eastern North Carolina 2009).

TMA (Treatment Modernization Act): The Treatment Modernization Act (TMA) amends and re-authorizes the Ryan White CARE Act from 2006-2009. In general, the guidelines serve to re-prioritize funding levels for different states. States in the US South received significantly more federal dollars than they had in years past. North Carolina, in particular, received a 6.5 million dollar increase in funding for the fiscal year 2007.

Funding level increases for southern states ushered in new regulations about how Ryan White money can be spent. In the South, adding new programs for substance abuse recovery, behavioral interventions, and medical care were a priority. In fact, 75% of all Ryan White funds were specifically targeted to core medical services, including physician appointments, prescription programs, and medical adherence counseling (USDHHS 2009).

VR (Vocational Rehabilitation):   VR is a state program that is administered through the North Carolina Department of Health and Human Services. The mission of the VR program is to promote employment and independence for people with disabilities. VR services include counseling, training, education, medical assistance, and transportation to qualified individuals (North Carolina Department of Health and Human Services 2009a).

WIC (Women, Infants, and Children):   WIC provides Federal grants to States for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risk (United States Department of Agriculture Food and Nutrition Service 2009).

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Curriculum Vita
Alyson O'Daniel

Date of Birth
April 30, 1977

Place of Birth
Evansville, IN

Education

Ph.D., Anthropology, University of Kentucky, Pending
Dissertation Title: Social Categories and Health Care Outcomes: HIV Positive
                African American Women and Survival in the Urban South

M.A., Anthropology, University of Denver, 2003
Thesis Title: "Too Much Life Goin' On": African American Women Surviving HIV

B.A., Anthropology, Indiana University, 1999

Research Funding

2008-2009	National Science Foundation Doctoral Dissertation Improvement Grant (Award #0823572)
2006	University of Kentucky Susan Abbott-Jamieson Pre-Dissertation Research Award

Presentations

2009	*"It's Like Some Kind of Run-around:" Institutional Network Strength as a Mechanism of Health.* Paper Presented at the 108th Annual Meeting of the American Anthropological Association, Philadelphia, Pennsylvania.
2009	*"It's On A Need-to-Know Basis, Booboo:" African American Women and HIV Disclosure in the Urban South.* Paper Presented at the Annual Meeting of the Society for Medical Anthropology, New Haven, Connecticut.
2007	*"Priorities" and Exclusion: Defining AIDS Care Through A Biomedical Lens."* Paper Presented at the 106th Annual Meeting of the American Anthropological Association, Washington, D.C.

2006	*"Meeting People Where They're At": The Role of Peer Advocates Within AIDS Care Bureaucracy, Harm Reduction Strategies, and the Facilitation of Working Client/Provider Relationships.* Paper Presented at the 105th Annual Meeting of the American Anthropological Association, San Jose, California.
2005	*Disastrous Disconnections: The Survival Needs of HIV Positive African American Women, Community Funding Competition, and HIV Service Provision.* Paper Presented at the 104th Annual Meeting of the American Anthropological Association, Washington, D.C.

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Professional Experience

Fall 2009	Part-time Instructor, University of Kentucky Department of Anthropology (Introduction to Anthropology 101)
Summer 2009	Research Assistant, University of Kentucky for Dr. Mary Anglin (breast cancer activism)
Spring 2009	Primary Instructor, University of Kentucky Department of Anthropology (Introduction to Anthropology 101)
Spring 2007	Teaching Assistant, University of Kentucky Department of Anthropology (Anthropological Field Methods 490)
Fall 2006	Primary Instructor, University of Kentucky Department of Anthropology (Introduction to Anthropology 101)
Spring 2006	Teaching Assistant, University of Kentucky Department of Anthropology (Anthropological Field Methods 490)

Fall 2005	Primary Instructor, University of Kentucky Department of Anthropology (Introduction to Anthropology 101)
Summer 2005	Research Assistant, University of Kentucky for Dr. Mary Anglin (breast cancer activism)
Fall 2004	Teaching Assistant, University of Kentucky Department of Anthropology (Cultural Diversity in the Modern World 160)
2003	Historical Research Consultant, Bradley David Productions, Evansville, IN (independent film called Novem)
2002-2003	Volunteer Grant Writer, The People With AIDS Coalition Colorado, Denver, CO
Fall 2002	Program Evaluator and Needs Assessment Analyst, The People With AIDS Coalition Colorado, Denver, CO
Winter 2002	Research Assistant, University of Denver for Dr. Tracy Ehlers (condom use negotiation)
2001-2002	Research Assistant, University of Denver for Dr. Richard Clemmer Smith (Native American pottery styles)
Fall 2001	Teaching Assistant, University of Denver Department of Anthropology (Introduction to Anthropology 100)
Fall 2000	Teaching Assistant, University of Denver Department of Anthropology (Introduction to Anthropology 100)

Professional Memberships
Society for the Anthropology of North America
Association of Black Anthropologists
Society for Medical Anthropology