CHAPTER ONE

The Politics of Intersectional Stigma for Women with HIV/AIDS

I am sitting in a living room, in Detroit, full of decoratively placed plants. The colorful plants help to make the sparsely furnished room feel comfortable. My attention is drawn back to Nicole, a forty-two-year-old African American woman sitting in front of me on the couch. She is wearing an amber colored dress. Her braids are held back by an attractive hair tie, and she possesses a clear cadence to her voice. We have been talking for about an hour, and all my senses are alert. Nicole is about to tell me more of her recent political projects. From a manila folder, Nicole pulls out some materials to show me. Her file is crammed with press clippings, letters from Congresspeople, and grant applications.

Nicole is a former sex worker, former small-time drug dealer, and former crack addict. She contracted HIV five years ago; she has been and continues to be a stigmatized woman. Yet these categories alone I mention above contribute little to understanding her life when she was those other things, nor, more importantly, what her life has become now. She is a woman living with HIV who has become politically engaged. She is one of the foremost people involved with women and AIDS activism in Detroit. That afternoon we talk about Detroit politics, black male and female relationships, and prostitution. After talking with Nicole I feel that I am on to “something” about women and political engagement; I am learning from her. (Fieldnote 1996)

This fieldnote, written in 1996, initiated a new way of thinking about the various women I had been studying in Detroit. What had begun several years ago as a research inquiry into the status of female lawbreakers, a “story” about crime, prostitution, and the ravages of crack cocaine use, had instead over time become transformed into a “story” explicating the lives of stigmatized, politically active HIV-positive women. This story was recast to highlight women (formerly active female lawbreakers) who after being diagnosed with the HIV/AIDS virus changed their lives. Finally, it evolved into a story about stigma, struggle, and a group of women who are nontraditional political actors. The process of how Nicole and other women reconstituted their lives once they became HIV-positive, how they created and utilized a web of nontraditional resources and participated in their communities became the cornerstone of this
research. Their life struggles and political involvement help to question what scholars know about political participation for stigmatized women. The process by which these women have transformed themselves and exerted their rights in a democratic society deserves scholarly attention—and is a story worth telling.

There are three central elements to this story, making this story worthy of further explication. They are the actors (the women), the event (acquiring the HIV/AIDS virus), and the outcome (their political participation). Each of the elements is interdependent with the others, and they work together to create meaning. The questions that emerge from the telling of this story include: (1) How does such a severely stigmatized group of women participate? (2) Why do they participate? (3) What types of activities constitute participation for the women?

This chapter provides an overview of how the women “arrived” at this moment as politicized people, and what this arrival epistemologically ushers forth for capturing the dimensions of stigma and participation. Throughout, I reframe central questions about what constitutes political participation, including: How can we expand the notion of politics to include my respondents’ experiences? Drawing on sociological insights about “community work” as political, I argue that in order to capture the dimensions of stigmatized women’s work in their communities, a much more generous assessment of politics must be deployed. In the second half, I introduce the theoretical framework of intersectional stigma that helps explain the challenges stigmatized people face when becoming politically active. Intersectional stigma furthers the investigation into how people are situated within axes of social identities that often confer power and privilege.

Let us now return to the respondents. We begin with an overview of the story, followed by an argument designed to broaden our notions of politics.

An Overview of the Story

Sixteen women’s lives comprise the foundation of this study. Their life stories are neither transparent nor easy for a researcher to characterize. Before becoming HIV-positive, most had lived lives that would make them suspect to the majority of Americans. They are primarily women of color. They were sex workers, drug users (primarily of crack cocaine), and lawbreakers (engaging in criminalized activities) in every sense of the word. Personally, many of these women’s lives were complicated by domestic violence, childhood sexual trauma, sexual assault, family substance use, and intermittent poverty. Before they became HIV-positive, aspects of their lives could be characterized as troubled, difficult, unmanageable, and depressing. They were women whom the average person would not have
taken notice of, identified with, nor thought worthy of any special attention. If anything, they were women whom society had either given up on or directed particular punitive policies, agendas, and programs against.

These sixteen women were diagnosed with the HIV/AIDS virus from 1986 to 1996. During their diagnosis, they were perceived and identified by medical providers and others involved in the medical arena already as “deviant” women. The circumstances surrounding how the women discovered their HIV-positive condition might surprise, or even shock, the average person. The experiences they recounted were humiliating, painful, and stigmatizing. I have labeled their remembrances, and subsequent actions because of these remembrances, under the rubric narratives of injustice. The narratives of injustice suggest to us the mistreatment the women faced due to the specific conditions of their experience. These events created the catalyst for respondents to embark upon an individual and collective quest grappling with what it means to be a stigmatized HIV-positive woman.

Collectively, these women represent populations (women of color, drug users, urban residents, low-income women, drug-using prostitutes) that are among the fastest growing groups in the country with HIV/AIDS. They represent the new “face” of populations with HIV/AIDS in this country. They are a group of women with HIV who are highly stigmatized because of their former lifestyles. Also, because they have overlapping membership within the groups mentioned, they embody the structural ways in which the disease highlights long-standing areas of inequality along race, class, and gender axes.

Infection with the HIV/AIDS virus has the capacity to make previously hidden people public. Groups who were marginalized before (e.g., gay male communities) have come into public view because of the ravages of HIV/AIDS. For some, however, this disease can increase invisibility, causing individuals to recede further into marginality and stigmatization. Some people respond to the public labeling of HIV, and resulting stigma, with resignation, shame, and death. This story, about these women, could have ended here without another passing thought. But it does not.

There are other HIV-positive people who refuse to be made invisible, who use their rage and fear to mobilize and confront existing power structures. The women discussed here fall into this category. The rest of the story is about how these sixteen women responded to the HIV/AIDS crisis in personal ways that spiraled out to touch and intersect with their communities and the political realm.

Intersectional stigma is a distinctive aspect of their story. What makes their experience of the HIV/AIDS virus and their participation different from other counterparts of people with HIV is the influence of intersectional stigma. Intersectional stigma is a theoretical framework composed
of the recognition of and attention to intersectionality (or acknowledgment of race, class, and gender subordination as interlocking forms of oppression), and stigma (or the ways in which people become socially defined as “other”). Intersectional stigma allows me to theorize about the distinct ways in which marginality is manifested and experienced. Furthermore, intersectional stigma represents the total synchronistic influence of various forms of oppression, which combine and overlap to form a distinct positionality.

Through the prism of intersectional stigma, we can theorize that given that the women were already socially positioned as “deviant women,” the effect of the HIV/AIDS virus was to dramatically add to and combine with their existing social marginality. This phenomenon, I argue, is in part related to the fact that contracting the HIV/AIDS virus as a woman who has a crack cocaine and sex work background is incredibly stigmatizing. The framework of intersectional stigma helps explain the reasons why when initially diagnosed with HIV they received negative treatment from family, medical providers, peers, and others. Because of the onus of intersectional stigma, they experienced a qualitatively distinct form of stigma. Additionally, their HIV-positive status and experience of intersectional stigma highlighted other facets of inequality in their lives. Coming to terms with why they were stigmatized as people with HIV forced them to ask deeper questions of themselves. The questions once raised would cause a search for answers, which would continue to change and shape their lives.

Through this process they embarked on the path of “life reconstruction.” Life reconstruction is the underlying foundation facilitating women’s political activities; it consists of the specific ways in which women redirected areas of stigma that enabled them to deal with the HIV/AIDS virus. The result of this process was minimally twofold. First, it enabled them to develop a “public voice” about being a woman with HIV; second, it allowed them to become aware of resources that would form the underpinning for their later political activities. The resources gained by the women during the life reconstruction process were not usually those of professional status and mobility, higher education, or large amounts of money. These are the resources usually associated with political participation. The women, however, discovered and developed both external and internal resources including faith and spirituality, substance abuse treatment, therapeutic work on early sexual trauma, a reliance on self and female peers, an introduction to HIV/AIDS advocacy, and ideas about activism.

Regarding political participation, there is a generally accepted idea of a hierarchy of mobilization. This idea suggests that a person often begins being politically active at the “lower” end of the spectrum, and then moves into the “higher” end. Or, stated another way, a person moves from informal to formal political activity. Political activity is often not
seen as an end within itself, but a constant progressing toward more complex forms of participation (Rosenstone and Hansen 1993; Ackelsberg 1988). Interviews with the politically active HIV-positive women forced me to reexamine this theoretical “hierarchy of mobilization” from these women’s perspectives.

For my respondents, participation did not emerge as the result of an isolated, abstract process, a process that is so often described by many political participation scholars; their participation is embedded in a relational dynamic (for critiques of the democratic process as isolated, abstract, and universally male see Ackelsberg 1988; Bookman and Morgen 1988; Flammang 1997; Nelson 1989).

When we think of people exerting political power and influence in our society, we tend to think of people casting votes, forming political action committees, or deciding to run for office. Yet many types of political “work” hold American society together. With a renewed sense of optimism, and faith, the women, through their efforts, slowly became part of the political process and affected the lives of HIV-positive people. And yet their participation did not culminate with someone running for office—providing for an easy, neat, and linear ending to their participation and the story.

The best method to capture the ways in which they articulated the work they did in their communities and the meanings they made from it is reflected in my concept of blended and overlapping roles. Blended and overlapping roles draw on the structure of their paid and unpaid activities in the community. Their use of blended and overlapping roles also allowed them to draw on various kinds of knowledge and expertise.

The Women and the Activities

The activities respondents participate in range from “formal” political action like voting to “informal” political action. Most respondents have moved into various types of grass-roots-level political participation, primarily in the areas of HIV/AIDS issues. These latter activities include undertaking HIV/AIDS outreach and education; petitioning the state of Michigan for monies for HIV/AIDS research conducted on women; and fighting for better substance abuse treatment programs for lower-income women. They have petitioned the legislature about bills that would affect HIV-positive people. Other participants have attended national conferences (as panelists and invited presenters) and have spoken to women and young girls at different facilities including prisons, churches, schools, and community centers. A few have made appearances on both radio and television; others have written opinion pieces for newspapers. Women’s efforts have resulted in the widespread usage of pre- and posttreatment
counselors in most HIV/AIDS testing sites. Working with city officials, they have advocated for better-designed support and service programs for women with HIV and their children. Some have helped design those programs. They have testified in public hearings related to HIV/AIDS issues. Many of these activities helped them to stay both self-empowered and community focused.

Broadly construed, the primary concerns of my respondents that lead to political engagement include HIV/AIDS education, HIV/AIDS prevention, health care, child welfare, community development, and crime. Overall, these types of informal and grass-roots-level organizing are thought of as a common pathway for women as first political experiences (Randall 1987; West and Blumberg 1990).

To continue this discussion it is appropriate to look closely at the situation of U.S. women with the HIV/AIDS virus. Just what has been the virus’s impact on women in the last decade?

The New “Face” of HIV/AIDS

_The women HIV affects are more varied than the virus’s own mutations._

_Nothing better epitomizes the multiple voices and visions of AIDS than women’s experiences of the epidemic._ —Nancy Stoller, _Lessons from the Damned_

The HIV/AIDS virus is a pandemic issue. The United States is undergoing a significant shift in the populations the virus is affecting. Women continue to increase as AIDS patients (Phillips 1997). Deaths caused by AIDS declined in men during 1996, but increased in women by 3 percent (Phillips 1997). This change has come in what seems like a short span of time, little more than a decade. The HIV/AIDS virus is now seen as reaching a plateau for some groups of men in the United States, but still swelling for women. The acquisition and treatment of HIV/AIDS in this country underscores several of the structural realities of class, race, and gender. Among women of color, African American women, in particular, have been hard hit by the spread of the virus:

Between 1985 and 1988, the rate of HIV-infection quadrupled among women of color, many of whom reside in poverty-stricken inner city communities. Today, women of color constitute 72% of all women infected with HIV, 53% of whom are African American and 20% of whom are from Latin America. Urban mortality rates indicate that AIDS is the leading cause of death among African American women between the ages of 15 and 44 years and amongLatinas between the ages of 25 and 34 in New York and New Jersey. It is predicted that
in the twenty-first century, AIDS will become the leading crusade of death among minority women of childbearing age. (Chu, Buschler, and Berkelman 1990; as cited in Land 1994, 356)

By recent Center for Disease Control and Prevention (CDC) statistics AIDS is now the third leading cause of death for African American women among the age group of twenty-five to forty-four. AIDS among African American women could be considered a crisis that affects not only individual women but their communities (see Land 1994). HIV/AIDS risks for black women, as for other women, are complicated by structural factors of inequality.

Women acquire the HIV/AIDS virus from different routes of transmission than men. Drug use, particularly intravenous drug use, as well as an exacerbating influence of sex-for-crack exchanges have been implicated as contributing to the rise of infection among women (Phillips 1997). Although drug use was known in the early days as a factor contributing to HIV/AIDS transmission, recent information has shown that it is of greater importance than previously believed. Additionally, the co-determining phenomenon of various types of drug use, the prevalence of certain drugs in large urban areas, and the fact that the majority of women infected live in cities with populations over 500,000 all speak to the interrelated problems of race, class, gender, and marginality (Phillips 1997). It is now an agreed-upon observation that Stoller acknowledges: “HIV among women is a disease of the poor, uneducated, and the ghettoized” (1998, 11). The degree to which women have been affected by the disease is inseparable from the historical scars of inequality in American society.

Women’s Community Work: Broadening the Definition of What Constitutes Politics

In the last twenty-five years there have been a number of revisions to the traditional understanding of women and politics, moving away from gender as a simple and transparent category to a growing interest in gender as a multifaceted dimension of analysis. This has produced central questions, arguments, and revisions of what constitutes the political terrain for women. Janet Flammang succinctly discusses the ways in which dominant approaches in understanding women’s political participation are lacking:

In order to understand women’s political participation, conceptual lenses needed to be refocused in three ways: from the military state to the social welfare state, from the state to the community, and from interest groups to voluntary associations. (1997, 96)
Flammang’s insight is precisely astute for this discussion. The new theoretical investigations for gender and political participation involve redefining what activities constitute the “political,” particularly as it intersects with what has been called “community work.” Community work encompasses a diverse array of activities that fall in the realm of nonelectoral participation.

Until recently, examination of working-class women’s and lower-income women’s political activities in their communities had been missing from the rubric of women, politics, and participation (Bookman and Morgen 1988). Bookman and Morgen (1988) helped spark this new direction by arguing for an overall redefinition of politics to include activities women are routinely immersed in. These activities include grass-roots-level organizing in the communities in which they live. Moreover, investigations into activities that define “community work” and the terrain of women’s links in communities have begun to counter that absence. This new direction is helpful in countering the assumption that certain types of women do not politically participate. There have been significant reconceptualizations of politics through multidisciplinary inquiry, which combine questions of women’s political agency, community activism, and race, class, and gender analyses (see Naples 1998). The scholarship originates from diverse sources, including multiethnic studies, history, anthropology, and sociology. Activists and community organizers have also contributed to this literature. Recent interest in community work has also been fueled by interest in how the “war on poverty” programs created state-funded employment and volunteer positions that women primarily filled (see Gilkes 1988, 1994; Naples 1991a).

As women’s activism at the community level is being unearthed, it portrays a historically and theoretically different picture of women’s politicization from what we have come to believe. Traditional categories used to ascertain women’s participation have masked women’s militancy (Naples 1991b). Additionally, the idea that all participation comes from general self-interest is a model that does not resonate with women’s forms of participation and reasons for participation (Ackelsberg 1988). Women’s involvement in charitable organizations to community groups has been an important part of women’s political landscape (Cott 1987; Giddings 1984). Naples argues the study of women’s community-based activism in the twentieth century “has also contributed significantly to the re-conceptualization of sociological categories—especially ‘politics,’ ‘work,’ and ‘family’ typically used to analyze social life” (1998, 3). Naples asserts that “women’s unpaid work and community activism were essential for the formation of the modern social welfare state” (1991a, 318).

It is precisely the ways in which scholars are conceptualizing community level organizing (also referred to as “community work”) and other forms of participation that begin to illuminate the activities of the Detroit women. Much of the work they engage in is on behalf of the HIV-positive
community and includes informal participation. Our current ideas about participation have to be broadened to include community work that involves paid and unpaid labor.

Some scholars have investigated how women’s community unpaid and paid work is connected with and intersects the political realm (Naples 1994; Gilkes 1980, 1988). Scholars have argued that community work and notions of community highlight avenues of social change: “One of the most consistent themes to emerge from feminist analyses of women's political praxis is the significance of constructions of community for women’s politicization and social action” (Naples 1998, 330).

Community work has been defined two different ways in the sociological inquiry into women’s activities: as paid and unpaid activities. Community work has often been defined as work or labor outside the home: “It is the labor these women perform often in addition to work in the household and the labor force” (Gilkes 1994, 230). Community work can constitute nonelectoral forms of participation that serve to help, define, and protect a community against external threats. Some studies of community work highlight the ways in which women of color have worked to mitigate racism in their communities (see Gilkes 1988; Naples 1994).

Gilkes has written extensively on the role of community activism by middle-class African American women (see 1980, 1983, 1988, 1990, 1994). She studies how a number of African American women working for the state (programs developed in response to antipoverty campaigns) helped create a voice for the ongoing struggles of racism directed at their communities; they often served as an interface between state and local agencies. She details how some black women constructed professional careers through the avenues of community work while simultaneously fighting on behalf of community interest. Gilkes (1994) argues that this type of sustained effort can be a route community workers utilize to synchronically challenge racism. Community work, Gilkes documents, itself covers a “wide range of tasks”:

Community work consists of the women’s activities to combat racism and empower their communities to survive, grow, and advance in a hostile society. The totality of their work is an emergent, dynamic, interactive model of social action in which community workers discover and explore oppressive structures, challenge many different structures and practices which keep their communities powerless and disadvantaged, and then build, maintain, and strengthen institutions within their community. These institutions become the basis for the community’s political culture. The women generate an alternative organization, and a set of commitments to group interest are the basic elements of the community. They work for the community that they themselves re-create and sustain, a mutually reinforcing process. (230)
Gilkes continues to map out an expansive definition about the nature and scope of these activities. The activities she chronicles help shift the focus from macrolevel settings to microlevel settings:

Community work is focused on internal development and external challenge, and creates ideas enabling people to think about change. It is the work that opens doors to elected and appointed positions in the political power struggle, and demands and creates jobs in local labor markets and the larger economic system. Community work also focuses on changing ideas, stereotypes, and images that keep a group perpetually stigmatized. Community work is a constant struggle, and it consists of everything that people do to address oppression in their own lives, suffering in the lives of others and their sense of solidarity or group kinships. (231, emphasis added)

Naples has expanded on these microlevel dimensions, delving into the community work of black and Latina women whose self-defined categories did not fit with traditional conceptualizations of politics (1991a, 1991b, 1994). Naples articulates a compelling understanding of how some black women’s and Latina women’s activism translates into “activist mothering,” where a concern for women’s work in low-income neighborhoods consisted of the interconnections between political activism, mothering, community work, and paid labor (Naples 1994). Her analysis of “activist mothering” captures radical notions about the political activities and “self perceptions of their motherwork” (Naples 1994). Generated from oral narratives, it challenges the traditional definitions of labor, socially reproductive work, and politics. Throughout these works there is a focus on social change and everyday politics.

One of the keys to understanding women’s community work is that women maintain social affiliations and networks from communities they grew up in. These networks are drawn on for political work. Women community activists are also “politicized through specific experiences or struggles that they must first reflect upon before they can take effective action” (Naples 1998, 332). This process involves discussing feelings and ideas with others who may have had similar troubles:

This interaction between the everyday life experiences of injustice, inequality, and abuse and processes of reflection occurring within social networks with specific gender, race, and class divisions opens spaces for oppositional consciousness and activism. The broader cultural, political, and economic environment also forms a powerful material context framing their lives and profoundly shapes how activists defined their relationship to specific struggles, what political actions might be effective, and what resources are available. It also structures the very grounds upon which many of their experiences are built. (Naples 1998, 332–33)
Race, class, and gender have not been mutually exclusive topics within studies of community work, but have been used as different kinds of conceptual focuses since the initial investigation on women’s activities (see Bookman and Morgen 1988). As research emerged, women of color were documented as playing a central role in the extent to which they were participants. Probing the differences between white women and women of color community workers has been an important theoretical goal in the evolution of research on community work. Naples notes:

However, while white women and women of color may describe their motivation for community work as an extension of their gender identities, their differing standpoints shaped by race-ethnicity, class, sexual orientation and region of residence influence how they define their family’s and community’s needs, as well as the political strategies to accomplish differing goals. (Naples 1992, 443; Naples 1998; Gilkes 1988; Susser 1988)

Therefore from these insights Naples challenges scholars to look to broader evidences of political activity, and argues that if “we turn our attention to the community-based work of African American, Latinas, and other women of color, we are forced to reconceptualize our understanding of community work, political activism, mothering, and by extension, our analyses of labor” (1994, 224). This expansive rubric of community work is theoretically adopted in understanding respondents’ activities. As later chapters will demonstrate, this study of respondents’ activities in the area of HIV/AIDS is an extension of theoretically disentangling the various layers of where and how stigmatized low-income women’s participation manifests.

I argue that through their efforts they helped to create and re-create a sense of community, and that their labor overlaps and often resists easy public or private distinctions. They struggled on behalf of an extensively defined HIV-positive community. Although the focus in much of the research conducted by Gilkes (1994) and others (Sotelo-Hondagneu 1998; Pardo 1998; Park 1998; Stern 1998) has examined community work derived from definitions of community that include race, language, ethnic background, and discrimination, other research has demonstrated how women engage in community work in a wide array of settings, against a number of oppressive situations (see Bookman and Morgen 1988; Krauss 1998 for toxic waste and struggles by white working-class women; Naples 1998; Taylor and Rupp 1998 on lesbian activism; Wittner 1998 on battered women’s activism). Respondents’ activities fit within and expand on current research and definitions of community work. Including women’s unpaid and paid activities within the HIV/AIDS arena demonstrates the broadness and flexibility of community work as a way to analyze participation on various social issues.
Moreover, incorporating insights about community work into questions about gender and political participation yields gains for both sets of inquiries. Looking at stigmatized women expands the research on community work because there has been little research that discusses the community work of severely stigmatized women. Incorporating community work within traditional inquiries of gender and political participation is a logical extension of critiques already put forth by scholars working in diverse fields. Community work captures a more comprehensive spectrum of American women, and it potentially provides an in-depth mapping of informal political participation.

We turn now to a brief explication of how roles help us to understand the Detroit women’s activism and its connection to community work.

Roles
How do women work on behalf of the HIV-positive community? What activities do they undertake? This question is best answered with an attention to blended and overlapping roles, roles that combine paid and unpaid work for the Detroit women. Advocates, activists, and helpers are the categories used to describe and explain their roles and contour of their activities. Chapter 7 documents the fluidity between the roles. These positions are self-defined and form a web of relationships with local, city, and state government. They are not solely identity based. The type of activities the women engage in help define their community and are consistent with other goals that research on community work has explored. Their activities on behalf of the HIV-positive community include:

- defining the HIV-positive community
- renegotiating and redefining stigma about people and the disease, dispelling an “us versus them” mentality
- performing “face-to-face” work
- creating cultural products and events about HIV
- involving themselves in the survival and quality of life of HIV-positive people
- working for material and social change

For their efforts, they have received what other scholars have called a “community mandate” (Gilkes 1994). The term refers to the ways in which community workers receive status or recognition from other community members for working on behalf of the community.

The role of advocate usually involves some paid work within a city agency, nonprofit organization or community center. Advocates use their positions to advance critiques of the system; Activists are women who engage in more direct confrontational strategies; they are also women who
have felt somewhat marginalized in larger HIV/AIDS community projects. They are interested in producing cultural products, products that challenge negative images of HIV-positive people. Helpers are bridge women, often trained in some form of advocacy; they also facilitate other women’s participation in community activities.

Not only is important for us to perceive women as political actors, but it is essential for scholars to pay attention to what venues women are politically in. As Vicky Randall suggests, interested scholars need to take note of the various activities that women engage in, activities that look less like conventional politics. These include makeshift organizations, self-help projects, popular protests, and the like. She argues that all of these arenas might be a fruitful place to look for women’s sustained activity (Randall 1987). My work suggests that researchers need a reevaluation and reconceptualization both of how stigmatized women choose to organize and of where they organize or participate. Often the “sites” where they undertake political work—that is, drug treatment centers, support groups, community groups, and so forth—tend not to be recognized by researchers. For respondents, the places where political activities/community work occur straddle conventional public and private realms. The physical locations include micro- and macrolevels. Some of the macrolevel physical spaces include hospitals, churches, neighborhoods, community centers, agencies, schools, and prisons. Examples of the microlevel physical spaces include a woman’s home, picnics, hair salons, support groups, and conferences (not city funded).

Features of their political process, based on their role structure, could also be categorized as experientially focused, often black-female led and participatory/community oriented.

**Politics, Women, and HIV/AIDS**

Scholars have begun to take interest in how HIV-positive women have become politically active and empowered. The scope of this literature has evolved through the fields of public health, social work, community organizing, nursing, sociology, and anthropology. Theoretically, there has been sustained attention to how women with the HIV/AIDS virus (and others) are involved in a broadly defined HIV/AIDS social movement.

There exist methodological and theoretical gaps in terms of explaining and providing rigorous examples of the various processes of empowerment for women with HIV (including catalysts for participation and different routes to and expressions of participation). Early work sought to document grass-roots level organizing in various communities (ACT UP/NY Women and AIDS Book Group 1992). Most of the documentation came
from activists, who were interested in making women with HIV/AIDS visible and also providing political strategizing and organizing tips for women with HIV (see Carlomusto 1992; Dixon 1992; Wolfe 1992). This work nationally documented videos, demonstrations, outreach, and peer education programs. Early on there was a recognition that social context influenced pathways to different women’s HIV/AIDS participation (Schneider and Stoller 1995). For example, the homophobia as well as the medical profession’s established responses that “lesbians are not at risk” worked initially to silence lesbians. Lesbian and bisexual women were involved in HIV/AIDS activism on behalf of their friends and associates in gay male communities. It was only after numerous vituperative discussions and dilemmas about what defined “lesbian sex” (and the fact that lesbian-identified women were contracting HIV) that lesbians mobilized on behalf of themselves and their community.15

Heterosexual women initially confronted few services tailored to women, difficulty in accessing services, and invisibility issues (i.e., “nice girls don’t get HIV/AIDS”; see Grove, Kelly, and Liu 1997). They also had to face and negotiate condom use and to challenge certain types of sexual behaviors with male partners—a difficult situation for most women, given gender socialization (Schneider and Stoller 1995; Act/UP New York Women and AIDS Book Group 1992). Researchers have focused on the inadequacy of services women with HIV/AIDS face and the lack of information provided to women (see Land 1994), but the experience of being treated poorly at the time of diagnosis or the impact of multiple stigmas have not been widely discussed.

For respondents, pathways to participation and empowerment begin with the acquisition of the virus. Activity did not begin for these women until after they were diagnosed. This makes them similar to some other groups, particularly women, who found themselves HIV-positive. HIV provided a catalyst for them, but it is argued here that this was also related to the social context surrounding the acquisition of and disclosure of the virus. Their route to activism was marked with the trials and tribulations of being a stigmatized person because of drug use and prostitution. This had consequences for the information they received and how they perceived their treatment. As is discussed fully in chapter 4, the women who discovered they were HIV-positive cite the many distressing circumstances surrounding their diagnosis of the HIV/AIDS virus. Briefly, health officials did not give them proper information, and they were also given the message that the medical establishment could do nothing for them. Their impetus to change was not just the result of the HIV/AIDS virus, but it was also because they felt they were treated poorly and discriminated against (because of their drug use status and their sex work background); they felt as if they were given bad information when initially
diagnosed with HIV. Misinformation with HIV/AIDS is not uncommon, as other research has suggested:

Women of color receive greater misinformation about HIV/AIDS and underestimate personal risk (Kalichman et al. 1992; Marin 1989). Thus, they constitute a growing and vulnerable group at risk for the physical manifestations of AIDS and its psychological sequae. (as cited in Land 1994, 356)

It has been much later that scholars have turned to the subject of HIV/AIDS and examined the specific types of leadership women have held in that arena (Schneider and Stoller 1995). Slowly, narratives about the varied experiences of women have been incorporated in the “official record,” and what Stoller (1998) has called “histories of women with HIV/AIDS” have become more visible. Women on the front lines of HIV/AIDS activism as well as scholars have begun to write about the diversity of this phenomena (see Alexander 1995; Denison 1995; Fraser and Jones 1995; Greenblat 1995; Hollibaugh 1995; Lewis 1995; Lockett 1995; Stoller 1995). Methodologically, these are often short reflection pieces, which try to provide an account of the complicated dynamics women with HIV have faced and responded to in the last decade (see Schneider and Stoller 1995). Schneider and Stoller (1995) outline main themes in evaluating women’s leadership within the HIV/AIDS crisis:

(1) recognizing HIV/AIDS is a pandemic issue; (2) sustained attention to the social relationship to race, class, sexuality, and culture. The third theme is feminist social change, very broadly defined from the individual to collective; (4) emphasis on women’s skills and activities. (3–6)

Women who acquire the HIV/AIDS virus have used various means to increase their visibility, which include activities like developing support groups, outreach programs (set up in places from hair salons to churches), and protest demonstrations. Women who are not HIV-positive have also helped to spearhead some of these efforts, as well as been caregivers and resource people. Schneider and Stoller note the possibility for potential social change:

Consequently, women are in strategic positions to affect the course of HIV’s spread. Because of gender segregation in the workplace, women are the vast majority of employees in caregiving and health professions and seem to be the majority of workers in AIDS service organizations in most locations in the world. (1995, 1)

The political work women have undertaken has been constructed to help a larger populace who have direct stakes with women and HIV/AIDS issues, including policy makers, sex educators, social workers, health personnel, and the like (Schneider and Stoller 1995).
Throughout these analyses, the same problems emerge for understanding stigmatized women—it turns on the question of Who gets studied? As Schneider and Stoller acknowledge, early work on HIV/AIDS activism did not focus on outsider groups:

Poor women are often portrayed as unskilled, passive, and uninterested in politics. Like other struggles of poor and working-class women, the political worlds affected by the epidemic have been obscured and the activities of white, middle-class women have received most of the attention. In the AIDS epidemic, poor, working class and middle-class women are all actively engaged in efforts to change their lives and the institutions that serve them. (1995, 5)

This literature, while useful in its focus on women’s politicizing activities and HIV/AIDS, is conceptually lacking in its ability to help further explain the process of political consciousness that defines the group of women studied. As noted earlier, the pathways to participation are different for this group of women with HIV; so too is their process of political consciousness. The process(es) for women with HIV in relation to self-empowerment and political activity have not been sufficiently teased out by scholars.

Focusing on process allows for the dynamism of the women’s experiences in the sample to come to light. The phrase “life reconstruction” is used to signify the specific identifiable processes that allow women to construct, expand, reshape, or begin anew what it means to be a woman with HIV. The life reconstruction process also brought them into contact with specific resources, resources not usually identified by researchers.

There are two major components that define the life reconstruction process. They are substance use treatment/recovery and gender identity. Substance abuse treatment plays a central role in the beginning of the process; substance abuse treatment often provides a stable and supportive place for the women.

Schneider and Stoller (1995) suggest that women with the HIV/AIDS virus have to recast themselves and their roles within the private sphere. This focus on gender and political consciousness for respondents in my study is to capture the “micro-processes of gender socialization” (Schneider and Stoller 1995). This is especially fruitful inquiry, given that many of these women had previously either negative experiences with being a woman or had focused on other central features of their identity. One of the more tangible outcomes of this life reconstruction process for the women is the development of a “public voice.”

In summary, although there is a recognition of the importance of stigma (see Act/UP Women and AIDS Book Group 1992), there is scant research about how the pathways, context, and process of empowerment might differ for different social groups of women. When discussing the role of activism, concepts related to advocacy as gained through substance abuse treatment
are rarely mentioned. There is also not recognition that some women may overlap their HIV/AIDS advocacy with other roles or advocacy positions in their community. All of these factors are important considerations in capturing the picture of HIV-positive women’s community involvement.

**Politics of Everyday Life**

Embedded in the midst of this discussion of community work is the question of what defines political activity. Some scholars have argued that traditional versions of politics do little to explain how marginalized people experience the world (Cohen 1993; Kelley 1994). What community work often captures is the process of how people deal with “the politics of everyday life.” This dynamic interplay is quite hard to capture statistically or even to conceptualize outside formal political activity.

In this study, there are three sets of ideas about politics that are drawn on in assessing, explaining, and evaluating the activities of respondents. One focus is on empowerment, a term often mentioned by respondents in helping themselves and people in their communities. Bookman and Morgen use this definition in their work as a central concept in reframing politics for women:

> empowerment begins when they [women] change their ideas about the causes of their powerlessness, when they recognize the systemic forces that oppress them, and when they act to change the conditions of their lives. (1988, 4)

Naples in her study of women community workers offers her conceptualization, or schema, of “doing politics”:

> doing politics included any struggle to gain control over definitions of “self” and “community”; to augment personal and communal empowerment; to create alternative institutions and organizational processes; and to increase the power and resources of their community. (1991b, 479)

Finally, Robin Kelley, a historian, argues in his study of black working-class politics and culture that one must look at the margins, and go beyond what we think we know about politics to investigate new forms and meanings (1994). He suggests that sometimes “dynamic struggles take place—outside—indeed, sometimes in spite of—established organizations and institutions” (7). Kelley urges scholars to pay attention to the reasons why people participate, as opposed to solely studying the outcomes of participation:

> Too often politics is defined by how people participate rather than why; by traditional definition the question of what is political hinges on whether or not groups are involved in elections, political parties, or grass-roots social movements. Yet, the how seems far less important than the why, since many of the so-called real
political institutions have not always proved effective for, or even accessible to, oppressed people . . . I am rejecting the tendency to dichotomize people’s lives, to assume that clear-cut “political” motivations exist separately from issues of economic well-being, safety, pleasure, cultural expression, sexuality, freedom of mobility, and other facets of daily life. Politics is not separate from lived experience or the imaginary world of what is possible; to the contrary, politics is about these things, as to roll back constraints and exercise some power over, or create some space within, the institutions and social relationships that dominate our lives. (10, emphasis in original)

Foucault’s work (1979) also maintains that there is importance in paying attention to the diverse ways that people understand the distribution of power and the multiple sites of resistance to domination. In keeping with the above definitions and ideas about political activity, one definition of political activity for our purposes is purposive action, which helps to create and define a self or group identity, which then allows for individuals and groups to redress perceived injustices and grievances. This definition helps to open up new spaces between the public and private realms, where many of the activities of the women fall. Thus, the definitions of community work that have been referred to in this section combine with the idea of informal politics. I strategically use the terms activism, community work, politics, and political participation throughout the book to denote the range of activities that fall within the informal political realm. In doing so, I am offering up a richer, theoretical space in order to explore the suggestive contour of women’s involvement as political actors.

**Intersectionality**

I argue that women prior to their HIV-status, occupied social locations that disadvantaged them and made them vulnerable to multiple stigmas. This situation created a qualitatively different set of experiences for the women, as compared with other people who contracted HIV/AIDS. The HIV/AIDS virus acted as catalyst, which made them recognize and act on other aspects of stigma in relation to their identity. The concept of intersectionality and stigma are tied together to form “intersectional stigma,” the framework used in the analysis of women’s participation. Intersectional stigma, it is argued, affects identity, resources, and participation.

Perhaps the biggest problem political scientists, and other social scientists encounter when trying to study politically active marginal women or women of color or both (and other types of women on the social periphery) is the difficulty in capturing the degree and role of intersectionality and intersectional experiences.
There are two strands of intersectionality, and the concept of the intersection of race, class, and gender as it has developed within various feminist theory literatures, which concern us here. Intersectionality of experience in society, has been a driving theoretical focus, beginning specifically with women-of-color theorists trying to create relevant theory about the concept of multiple oppressions (see hooks 1981, 1984, 1989; Lorde 1984; Davis 1981, 1989; Dill 1979, 1983; Giddings 1984). Multiple oppressions, it is argued, can combine and create new and (often) unrecognized forms of discriminatory encounters in everyday life. Moreover, intersectional experience suggests that one’s social location is determined by the ways in which disparate oppressive conditions come together to foreground or highlight experience (Collins 1990; Hurtado 1989; King 1988; Smith 1987). Originally, many of these critiques were aimed at white feminists, who, it was argued, had obscured the experiences of women of color by positing gender as the only explaining locus of oppression or the most consistent, and salient one for all women. Similar critiques also arose from scholars engaged in separate areas of inquiry. These ideas mushroomed out across the academic arena due to their theoretical usefulness for exploring a nexus of questions about history, identity, and experience (see Andersen and Collins 1992, Haraway 1988; Harding 1986; Higginbotham 1992; for critical race theory and other jurisprudence see Crenshaw 1989; Williams 1991). These critiques reinvigorated feminist theory and captured the attention of theorists in many disciplines. Scholars reexamined central tenets in feminist theory through the prism of intersectionality, including experiences as diverse as labor, rape, sexual violence, and motherhood. Intersectionality has been sometimes called a metaphor, a methodology, a set of relationships, as a corrective to either/or thinking, and at other times as an analytical tool (see Andersen and Collins 1992; Brewer 1993; Chow, Wilkerson and Baca Zinn 1996; Zinn and Dill 1994; Collins 1995; Crenshaw 1997).

Concurrently, the second strand of intersectionality was discussed by Crenshaw (1989) in theorizing about black women’s experiences within the law. Within antidiscrimination law, she critiqued the legal system’s ability to recognize discrimination of black women. She argues that compartmentalizing experience—either focusing on race or sex—diminishes the usefulness of the law and is a detriment to black women. She argued that this single axis type of argument is replicated in feminist theory and antiracist politics. Detractors and skeptics of intersectionality argue that the concept is difficult to model quantitatively, and it is theoretically not always feasible to explicate multiple sites of oppression (see Daly 1993).

Some critics see intersectionality as arguing for smaller and smaller subcategories or for nonsensical mathematical models (see West and Fenstermaker 1995a for critiques of models proposed by advocates of race,

In response to these criticisms, Collins has argued that intersectionality is a willingness to see multiple sets of constraints and freedoms as an organizing frame for experience in U.S. society. Collins has labeled this idea as a “matrix of domination” (1990). This is a move toward understanding how all people are affected by this matrix and can occupy multiple and overlapping positions of oppression. Scholars have also stressed that intersectional factors and experiences are multiplicative, not simply additive (see Chow, Wilkerson, and Baca Zinn 1996; Anderson and Collins 1992; Collins 1990; Daly and Stephens 1994).

Collins (1995) responded to critiques of additive models of inequality that purport to represent the idea of intersectionality arguing that concepts of intersectionality emerged not just from academic inquiry, but also through the trajectory of contemporary social movements:

These links between theory and politics meant that, despite their historical differences, all three areas shared certain fundamentals. Each aimed to explain the links between micro-level experiences structured along axes of race, class, and gender, with the larger, overarching macro systems. Each reasoned that, if individuals could link their own experiences with oppression on a micro level with the larger macro forces constructing their social position, they could address some of the major social problems of our day. (492)

Single- or privileged-systems thinking (e.g., class over race) left much of the larger picture of inequality obscured. Collins notes that intersectionality is

a model describing the social structures that create social positions. Second, the notion of intersectionality describes micro-level processes—namely, how each individual and group occupies a social position within interlocking structures of oppression described by the metaphor of intersectionality. Together they shape oppression. (1995, 492; [emphasis added])

These positions are often in contrast with postmodern ideas where gender, race, and class concerns are sometimes recast as “performances,” “interactions,” “parodies,” or as “simple subjectivities” (see Collins 1995; Thorne 1995).

In a recent work Crenshaw (1997) elaborated on the various ways intersectionality can be used to halt monocausal explanations:

Intersectionality is a core concept both provisional and illustrative. . . . I hope to suggest a methodology that will ultimately disrupt the tendencies to see race and gender as exclusive or separable categories. . . . The basic function of intersectionality initially is to frame the following inquiry: How does the fact that
women of color are simultaneously situated within at least two groups that are subjected to broad societal subordination bear on problems traditionally viewed as monocausal—that is, gender discrimination or race discrimination? (552)

Crenshaw advances three different ways to understand and analyze intersectional experiences. The first is structural intersectionality, or “the way in which women of color are situated within overlapping structures of subordination. Any particular disadvantage or disability is sometimes compounded by yet another disadvantage emanating from or reflecting the dynamics of a separate system of subordination”—or phrased another way, “the material hierarchies” are relevant in discussing inequality (1997, 552).

The second understanding of intersectionality Crenshaw advances is “political intersectionality,” which refers to the ways in which political and discursive practices relating to race and gender interrelate, often erasing women of color. This seems more analogous to her original use of intersectionality in the law. She suggests that either/or propositions stressing either race or gender within a given context are not useful. The last variant of intersectionality is “representation intersectionality,” which suggests that popular culture produces images and representations that “converge to create unique and specific narratives deemed to be appropriate for women of color.” She argues that “the clearest convergences are those involving sexuality, perhaps because it is through sexuality that images of minorities and women are most sharply focused” (Crenshaw 1997, 554). She maintains these types of images are harmful purveyors of justifications for continued discrimination, violence, and abuse toward women of color.

These are useful ways to begin to operationalize concepts like intersectionality. Until recently, little attention has been paid to the intersections of oppression that many U.S. women of color face; oppression and discrimination are often different from the experiences of white women, relational to other women of color, and complex in the intersection and creation of gender identity (Crenshaw 1989, 1997; hooks 1984; Hurtado 1989; Collins 1991; Chow, Wilkerson, and Zinn 1996). Because there exist so few studies that attempt to explain women of color’s political experiences in the United States, there are even fewer that attempt intersectional analyses on any level.

Intersectionality is important to the integral argument about politics this book advances. Respondents are primarily women of color who are former lawbreakers. It makes theoretical sense to want to think through the ways in which their understanding of HIV and experiences of HIV and their later participation would have some relation to the intersection of gender, race, and class. Women in the sample cannot be referred to as “women” without a complex understanding of the ways in which their social location differs from that of other types of female political actors.
Second, it is argued that because of their social location they were *primed* to experience a devastating form of HIV-related stigma. When they became HIV-positive, all of the positions they occupied—drug user, sex worker, poor woman, were already concentrated, or saturated, with a set of representations and assumptions about those subject positions.

With this population and many others, applying concepts of intersectionality can help to crystalize and reinvigorate avenues of social science research. Understanding the complexity that results from the intersectional experience of HIV/AIDS provides an example of how further research can be carried out. I now turn to stigma, its importance to my theory building and its relationship to marginality.

**Stigma and Marginality**

Stigma is a *specific* form of deviance (Goffman 1971). Deviance is a broadly conceived concept widely deployed in sociological literatures (see Pфhul and Henry 1993). Stigma and the stigmatizing process, because they involve relationships of power and interaction, are a very useful concept for understanding how they might interfere with aspects of political participation for an individual or group. Stigma has restricted people’s political and social participation (see Plummer 1975; Schur 1983, 1980; Pфhul and Henry 1993). As Pфhul and Henry note, the “social limitations imposed on stigmatized people go beyond territorial protection and extend into almost every facet of everyday life” (1993, 177).

Studies of marginality and powerlessness revolve around how groups of people are effectively shut outside the political system, not necessarily by formal sanction or proscription, but by social sanction (see Cohen 1993 on African American mobilization on HIV/AIDS issues compared to gay men’s mobilization; Gaventa 1980 on quiescence and hegemony; Lukes 1974 on power). The question that might arise during this discussion is, Why isn’t these women’s participation thought of as an outcome of marginality? It could be argued that because the women belong to social groups who have had specific, long-standing problems with access to resources and power, those conditions should be a starting point for explaining and understanding participation. This group’s marginality is apparent. Why the focus on stigma and, later, on intersectional stigma?

Stigma and marginality are co-related factors in describing group experiences of “outsiderness.” But stigma itself is a rich and previously ignored concept as it relates to questions of political participation, affecting resources, access, and outcomes. Stigma informs our understanding at the individual and group level about informal mechanisms of societal exclusion. The realm of stigma constitutes what has been called a “language of
relationships” (Alonzo and Reynolds 1995, 304). It also can provide a map for how outsider groups might be able to overcome specific barriers to participation.

Stigma, in this instance, is one of the ways people who are marginalized experience themselves and describes barriers that interfere in their attempt to participate.

Stigma more effectively describes the societal reasons behind the overwhelming negative experiences respondents have faced in response to HIV/AIDS. Respondents’ experiences with stigma are rooted in specific cultural histories and ideologies; they are time, place, and context bound. The types of challenges they have faced are not just about belonging to groups without political power, although the women belong to relatively marginal groups in society.

Also, stigma once acquired is difficult to reverse or challenge. It may have “a temporal dimension in that they [stigmas] are ineradicable and irreversible as the terms ex-mental patient or ex-convict imply. In fact, stigma may follow us through the life cycle” (Alonzo and Reynolds 1995, 304). Stigma encodes itself into a person’s psyche with the resulting manifestations, including shame, self-hatred, internalization of broader group values, and repressed anger (Alonzo and Reynolds 1995). Schur argues that stigma and deviance involve far-reaching evidence of political norms. He posits “deviance [as] an inherent political issue.” He explains,

> By definition, since they are modes of devaluing and discrediting, the designation of deviance and the deviantizing of individuals involved the exercise of power and affect the subsequent distribution of power. (1980, 25–26)

Other authors have also commented on the issue involved in stigma, which is power: “Power relationships are central to stigmatization. Stigmatization is an exercise of power over people and a manifestation of disrespect for them” (Gilmore and Sommerville 1994, 1342).

Stigma also has the potential to affect resources. The resources that concern this argument are time, money, and civic skills. People who are stigmatized often have some difficulty in securing steady employment; they also tend to have less money (Phul and Henry 1993). Stigma does not necessarily affect free time. The development of civic skills, like education, are usually deterred or interrupted in a stigmatized person’s life. Because stigma has the potential to make one the target of violence and causes one to be avoided, these factors frequently mitigate against organizing (social or political) with other people (both stigmatized and nonstigmatized).

Marginality is related to concepts of disenfranchisement, but has often been conceived as more institutionally based, with a focus on material
resources. Cohen, however, in discussing marginalization leaves an opening for the development of research on stigma as it relates to the area of marginality and political processes:

The process of marginalization, through which groups come to be identified and exist outside the central institutions and systems of relating in society, can occur through the implementation of any number of strategies. Marginalization occurs and is reinforced when A, in some sustained manner, limits or excludes B from gaining access to, substantially participating in, or controlling those societal mechanisms—institutions, ideology, and social relationships—that determine the life chances of B. While the tactics of marginalization are various in nature, they generally take on three interrelated forms: ideological, institutional and social interactive. (1993, 40)

The ways in which marginality has been theoretically developed are not linked with interactional or other conceptions of stigma that inform Cohen’s category of societal mechanisms of marginality. But if we are to understand Cohen’s assertion that strategies of marginality are “multidimensional,” then it behooves us to place studies of stigma alongside and as evidence of marginality. Cohen notes: “To understand the true impact of a marginalized status we must search out the subtle ways in which inequalities are defined, maintained, and heightened” (1993, 60). Therefore, concepts of stigma and intersectional stigma are constructs that help illustrate features of marginality.

**Intersectional Stigma**

For some people, stigma has the potential to confer social power and to inhibit or curtail social power for others. Now, when we interlink the concept of **intersectionality** with the concept of **stigma**, we can use it as a way to illustrate the various ways women are specifically disadvantaged in relation to all phases of the HIV/AIDS virus. Intersectional stigma points to an understanding that women are not only **marginalized**, and socially situated (shaped by race, class, and gender), but that the category of “HIV-positive person” is loaded (from a stigma standpoint) with effectively negative perceptions about groups of people with the virus (e.g., drug users, crack cocaine users, prostitutes, lower-income women). Additionally, these negative perceptions are overlaid within the axes of race, class, and gender. Their experience of this disease illustrates the points of contact within structural realities of race, class, and gender and indices of stigma. Together, they have created a context for women’s experiences. HIV-stigma compounded each axis of inequality.
Other researchers have suggested the HIV/AIDS virus compounds and magnifies other types of stigma:

Although the stigma associated with HIV/AIDS is overpowering, individuals with the illness do not necessarily experience the same degree of stigma. Differentials in stigma experience can be explained, to a large extent, by variation in individual social identities and attitudes confronted in one’s social networks and reference groups. (Alonzo and Reynolds 1995, 305)

Land also discusses the devastating effects of HIV and stigma for women of color:

Although minority women with HIV come from various cultural backgrounds, they share many common issues and concerns. In general, they are the most isolated and least supported group with HIV and often experience considerable social stigma. These women present a shocking picture of what can happen to a people disempowered because of gender, race, ethnicity, and poverty. These women suffer the stigma of a disease associated with promiscuity, illicit drug use, and death. (Land 1994, 359–60 [emphasis added])

The effect of the HIV/AIDS virus shifted respondents from marginal positions into a highly specific discriminated-against collectivity. The concept of intersectional stigma provides purchase power in explaining qualitative differences in the experience of stigma and marginality. Intersectional stigma also begins to unpack why the history and trajectory of their participation looks different when compared to other groups who organized around HIV/AIDS issues.

There are four specific categories of stigma that women experience through their (pre- and post-) struggles with HIV/AIDS. The categories of stigma are drug use, sex work, sexual trauma, and the HIV/AIDS virus.

1. Drug Use. Crack cocaine is an incredibly stigmatizing form of drug use (see Inciardi, Lockwood, and Potteiger 1993; Maher 1992; Maher and Curtis 1992; Ratner 1993). Historically, women were often drug users, but in relative numbers to men, they were almost inconsequential (Inciardi 1993). The rise of female rates of crack cocaine use increased during the late eighties through midnineties. Some research has suggested that there existed similar rates of crack cocaine use and even HIV infection between women from rural areas versus large cities (Forney, Inciardi, Lockwood 1992). Despite these findings, I would argue that crack cocaine is associated with inner-city use. This does not mean that other groups of women are not stigmatized, but they are not immediately associated with drug use and prostitution as many of the women in my sample have been. One of the best ways I have seen this theoretically accounted for is by Austin (1992a), who discusses how stigmatized black women, in particular, have
no convenient narrative to explain deviant behavior. For example, they cannot fit into the “bad male gangster” image because that is an exclusively gendered identity within black communities with a history and ideology to support that framework.

As Campbell notes, “women who use illicit drugs embody both individual deviance and social failure” (2000, 1). In that representations of female drug users conjure up abusive, out-of-control, unfeminine, and unmaternal women, they are viewed as society’s “spectacular failures” (3).

2. Sex Work. Sex work is considered by many as a deviant activity, and is also criminalized in the United States (except in brothels in certain counties in Nevada). The majority of the women of the deep sample were street-level sex workers and were subject to stigma because of their actions. As they were also crack cocaine users, they faced compounded stigma in relation to their experiences of both street-level sex work and survival sex.

The phenomenon of sex-for-crack exchange transformed street-level sex work. Urban prostitution had historically been a consistent feature in the majority of U.S. cities from the early-twentieth century on (Rosen 1982; Hobson 1990; Mumford 1997). By the mid-to-late eighties, women involved in street-level sex work and prostitution represented a wide social and economic spectrum; some women were functional drug users and prostituted to make additional money; others were primarily there to make money and were not drug addicted. Some women thought of themselves as involved in semiprofessional or professional activities (Jenness 1993). These women were often able to care for their children and lead a semifunctional if stigmatized life. Street-level sex work was usually organized through one or more pimps, a person (usually a man) who watched over the women, bailed them out of jail, and set up a place for them to live. With the arrival and widespread use of crack cocaine, leading frequently to addiction, “survival sex,” involving bartering for drugs, became an increasing norm (Inciardi 1993; Ratner 1993). Use and addiction to crack cocaine often devolved into a crude and unequal bartering system, driving down prices for sexual services considered degrading and unacceptable by most of the women (drug users and non-drug users) and often driving out professional prostitutes. Tension between women from different backgrounds and worldviews occupying the same territory was not unusual (Maher 1992; Inciardi 1993; Ratner 1993). In the new urban landscape (and the resulting vacancies in the sex trade made by the flight of non-drug-using prostitutes), there was a new stream of women who were heavily addicted and who would sometimes undercut established prices based on local norms. The organization of street-level sex work and drugs changed spatially. The nineties saw the development of various places, often referred to as crackhouses, where men could have sexual
access to the women who smoked crack. Some women were not able to negotiate for better prices, leaving them more vulnerable to ridicule, abuse, and violence (Miller 1993, 1995).

As another accompanying phenomenon, often during extreme pharmacological addiction women (and men) became bolder and more aggressive during the time they are pursuing heavy crack cocaine use. During the 1990s, the combined interplay of drug use and sexuality was particularly pernicious. Prostitution was a feature of many urban communities (and many downtown areas identified as “red light” districts). Crack use changed the terms of the often liberal agreement to “look the other way” by either residents or law enforcement or both. If standard and organized practices of prostitution maintained a level of privacy and secrecy, crack cocaine and sex-for-drug exchanges were publicly bolder. Traditional prostitution with its secretive and its spatially enforced separation from the “respectable community” was undermined in this new era by this more public display of criminal exchanges. Crack use was a public affair. It often transferred the boundaries of sexual activity and drugs to public space—parks, streets, abandoned lots and buildings—in ways that were often shocking to community residents and others (Maher 1992; Wallace 1992).

America’s already conflicting codes and norms about drug use, prostitution, and accountability were strained even more by the eruption of crack cocaine throughout metropolitan areas. The political response to massive crack cocaine use (in particular female usage), with its resulting prostitution and challenges to public health was a punitive one.

3. Sexual Trauma. The category of sexual trauma refers to childhood sexual abuse and trauma experienced by over half of the respondents of the deep sample. Although sexual abuse in and of itself does not compose a deviant category, it is included here because women specifically felt stigmatized for being sexually assaulted. They also often experienced stigma within their families of origin if the abuse was confronted. It was a theme of central importance to respondents. This category involves feelings of shame and self-hatred and is overwhelmingly gendered.

4. HIV/AIDS. The focus on stigma is theoretically rich as it relates to the HIV/AIDS virus (and the position respondents found themselves in during and after diagnosis). HIV imparts a severely formative and traumatizing type of stigma.

The effects of the stigma of the HIV/AIDS virus have created and reinforced axes of inequality for women (Patton 1994; Stoller 1998). The response to the HIV/AIDS pandemic scapegoated several groups, and this scapegoating diverted public discourse into the direction of an “us versus them mentality” (see Alonzo and Reynolds 1995; Gilmore and Sommerville 1994; Patton 1994). There is a large literature that explores different facets of stigma that people with HIV/AIDS and their caregivers face (see Alonzo

It could be argued having the HIV/AIDS virus currently acts as a “master status,” overwhelming and eclipsing other aspects of an individual’s identity. Authors posit that “[t]oday, one of the most powerful and harmful stigmas is HIV-infection and AIDS (Gilmore and Sommerville 1994, 1341).” The scope of the virus and its impact is a crosscutting and unifying theme among researchers:

HIV and AIDS are manifestations of an extraordinary illness in terms of its potential for multidimensional stigmatization. . . . [As compared to other illnesses] HIV infection and AIDS are rather universal in their preponderant negative evaluation. (Alonzo and Reynolds 1995, 305)

Weitz argues that a “large part of having [the] HIV disease is the experience of stigma” (1995, 268), and that “[t]he threat of the HIV/AIDS virus is continuous throughout all phases—pre-diagnosis and post-diagnosis” (268). Weitz makes the argument that stigma related to HIV is a consistent feature of the illness:

Stigma is a concern during all phases of the illness, from before the diagnosis, when individuals must evaluate the risk of discrimination if they get tested for HIV, to the time when death seems inevitable and they must cope with the possibility of discrimination by funeral directors. (Weitz 1995)

The ways in which people understand HIV/AIDS is indicative of the pervasiveness of its stigma. Gilmore and Sommerville (1995) locate seven metaphors for the disease as manifested in language. They discuss several powerful socially constructed metaphors: AIDS as death, AIDS as punishment, AIDS as crime, AIDS as war, AIDS as otherness, AIDS as horror, and AIDS as villain (1994, 1351). Each of these metaphors conveys disturbing affirmations of prevalent notions about difference, deviance, and stigma.

The acquisition of the HIV/AIDS virus is stigmatizing and, as some would argue, will continue to be stigmatized despite different populations becoming infected, because it is primarily contracted through bodily fluids imparted sexually. Sexuality in and of itself is often a stigmatized activity (Brandt 1985). Stoller discusses HIV stigma and the way in which it reinforces other aspects of inequality:

That stigma may have been attached to AIDS and HIV primarily because of the marginalized social status of the majority of people with the disease. But all who are infected are tainted by it; it plays a “master role”—a role that dominates one’s perception of others. In the US, gender and race also function as master
roles, generating distinct behavioral responses in others, regardless of other roles that the individual inhabits, including occupational status. (1998, 136)

Gilmore and Sommerville have a slightly different understanding of how the HIV/AIDS virus compares to other epidemics including STDs:

Stigmatization related to AIDS differs in some respects from that related to other STDs. In the past, STD stigma often caused the persons to whom it was assigned to be seen as separate from society and its dominant communities, and as belonging to one or more separate stereotyped, minority communities. Members of these communities were seen to be “polluted,” morally corrupt, dangerous, irresponsible, etc. In contrast, already stereotyped and stigmatized communities have been further stigmatized by AIDS. (Gilmore and Sommerville 1994, 1349 [emphasis in original])

When we identify how the HIV/AIDS virus affected women in the United States, we can note that women on the very bottom of the social ladder have absorbed the majority of the stigma in relation to the HIV/AIDS virus. The women becoming HIV-positive in the last two decades are often women already considered deviant in some way. Women of color, drug-using prostitutes, and urban residents continue to constitute groups of women with some of the highest risks of infection who occupy the edge of the social periphery. From this we can surmise that as they were impacted with the HIV/AIDS virus, respondents were already positioned within a set of structurally deleterious social discourses, which would shape and determine aspects of their experiences with the HIV/AIDS virus. This argument does not, however, suggest that their experiences were predetermined or inevitable.

Patton argues that in understanding how the HIV pandemic is gendered, it is not so much about the question of the early invisibility of women that has caused major problems.

Particular and specific ways of carving up the category “woman” into a series of women-who-do-not-count-as-women was fundamental to the original paradigm through which researchers, policymakers, educators, and the media first understood the AIDS epidemic. (1994, 2)

She documents how these paradigms often were inflected with race and class bias. As Sacks notes, the way in which “AIDS discourses” have developed over the past two decades has helped to reproduce perceived differences between groups of women and not their commonalities:

AIDS discourses on women are overwhelmingly about women whose behavior puts them on either extreme of female deviance. One end of the pole are the prostitute, representing the apparently indiscriminate woman, and the pregnant,
HIV-positive woman, representing the unfit mother; at the other end lies the “innocent” woman—who became infected by her dentist; or by the sole unsafe activity of her life. (1996, 60)

Two scholars writing from an Australian context elaborate on this idea of the Western representation of HIV/AIDS:

[O]n the HIV-positive body is more often than not assumed to be male. Nevertheless, in a way reminiscent of earlier discourses surrounding syphilis, women living with HIV have been positioned as a potential source of infection. This representation has contributed to the widespread discrimination, with women being positioned as “dirty, diseased and undeserving.” (Lawless, Kippax, and Crawford 1996, 1371)

When we take these categories of stigma and combine them with the understanding of intersectionality (identified as the interlocking forms of oppression, which can be identified as separate, singular systems, but whose explanatory is greatly enhanced when they are seen as interactive and interdependent on each other), what we have then is not a methodology or just a theoretical example, but a narrative relationship between the interaction of these stigmas and social structure. The “piling up” of stigmas does not result just in a negative effect; it changes and transmutes the relationship between other aspects of identity and HIV/AIDS.

Moreover, the concept of intersectional stigma helps to highlight the area of sexuality as a powerful route of stigmatization—because the majority of the women acquired the virus through a combination of drug use and prostitution. Given the often degraded status of crack-using prostitutes that this research and others have discussed (coupled with representations in popular culture and news media), this route of HIV/AIDS transmission carries with it onerous stigma (see Berger 1998; Fullilove, Lown, and Fullilove 1992; Boyd 1993; Inciardi 1993; Maher 1992; Maher and Curtis 1992). Because the context of the HIV/AIDS virus for respondents involved assumptions of drug use and prostitution, consequently they were not granted the protection of “innocent victimhood.” Their experience of stigma that incorporates sexuality, race, class, and gender helps us to ascertain their unique responses to HIV and their struggles en route to political participation.

Intersectional stigma also illuminates the ways in which respondents are represented in discourses that speak to the interactive oppressive conditions that work to silence, thwart, hinder, and preclude participation in larger democratic forms of representation, debate, and process. They are composed of multiplicative influences that can singularly be identified as specific sites, but which collectively are not reducible to any of these
sites—it is the totality that creates the specific form of intersectional stigma. The cumulative and qualitative effect of intersectional stigma differentiates them from many other social groups who have the HIV/AIDS virus, makes their process unique. Studying this group gives an aperture to understanding the narrative relationship between stigma and political participation.

Let us turn now to research that supports the argument that paying attention to social identity in relation to stigma and HIV/AIDS is important. Grove, Kelly, and Liu (1997) in their qualitative work with white, heterosexual, middle-class women and their experiences of the HIV/AIDS virus, point to the specific ways in which social identity/location can insulate people from stigma. Drawing on the work of Bourdieu, the authors discuss social identity as a way to understand social and cultural capital. Their study suggests that because the women they interviewed were not identified with any of the risk groups associated with the HIV/AIDS virus, their respondents were often invisible to doctors as people with HIV risk (e.g., doctors would ask them, “Why do you want an HIV test? You’re not the type of person that gets that disease”). Moreover, the women did not experience any social exclusion or isolation and only very low levels of perceived stigma. The research finds that because of their powerful markers of social identity (in this case race, sexual orientation, and class) respondents could represent themselves as innocent victims, become “invisible deviants,” and remain blameless. Furthermore, the authors note that respondents “can reveal their stigma, but in doing so, they are neither discredited nor morally contaminated” (Grove, Kelly, and Liu 1997, 335). These are very suggestive indicators of the ways in which social identity can insulate against stigma, and evidence of the ways in which social perceptions about risk and disease structure experience.

Intersectional stigma also suggests that respondents’ multiple levels of stigma precluded their political affinity to other groups. Intersectional stigma differentiates them from other politically organized and agitating groups within the HIV/AIDS social movement—including sex workers and the queer community (lesbians, gay men, bisexuals, and the transgendered). It also explains not only their positionality, but also their experience of politicization in relation to HIV/AIDS.

To strengthen my argument, I turn to two groups of people who were also affected by the HIV/AIDS virus—gay men, particularly white gay men, and sex workers. By discussing these two groups, I argue that although these groups were relatively stigmatized in relation to dominant communities, they did not have the experience of intersectional stigma due to their connection with preexisting identities, and they were able to access organizational resources that helped them in responding to the HIV/AIDS virus.
Gay Male Mobilization

From the beginning of the HIV/AIDS epidemic it was characterized as a white gay male disease. Gay men, although marginalized within culture, simultaneously were situated to be able to respond to the crisis. They possessed significant cultural capital and symbolic capital and were able to cast themselves as if not experts, then at least as legitimate speakers within medical and social discourses (see Cohen 1993; Epstein 1991; Stoller 1998). Additionally, as Epstein notes, most affluent gay men in various cities had access to doctors and medical resources (1991).

Although, women, drug users, and others were present within early findings of people diagnosed with the HIV/AIDS virus, they had less cultural capital and were ignored (Epstein 1991; Schneider and Stoller 1995; Stoller 1998). The way HIV/AIDS (was and sometimes still is) imagined is through a white gay male lens (Stoller 1998).

Gay men are stigmatized within society. They have in the recent past and present been institutionalized because of sexual orientation, faced relentless discrimination overt and covert, and have been harassed, assaulted, and killed. However, they tend to command influence within the gay community as a whole, and also within their own social and economic networks. Despite their stigma, because they are male, gay men have had access to more resources compared to other stigmatized groups (even in the gay and lesbian, bisexual, and transgendered community); this phenomenon has been well documented (see Cohen 1993; Epstein 1991; Stoller 1998).

Despite societal prejudice, as they acquired HIV they were in a much better position to mobilize themselves. One factor that contributed to this was their ability to utilize a primarily male medical establishment (as well as gay male doctors and health professionals) and their own resources, and the ability to mobilize people from the standpoint of a shared group identity (Cohen 1993; Stoller 1998).

The organizing went into challenging the medical expertise of the health and medical establishment, challenging homophobia, and changing popular understandings of HIV/AIDS as a gay disease—and therefore unworthy of attention. Through organizations like ACT-UP, San Francisco AIDS Foundation, and the Gay Men's Health Crisis, gay men were able to plan, strategize, and respond to the HIV/AIDS crisis. They had peer groups, professionals within the community, and a wide resource base. Indeed, what distinguished them from other disadvantaged groups were their “economic access” and resources that helped build an “indigenous community” (Cohen 1993, 277). In the past ten years these groups have been more responsive to the diverse needs of the HIV/AIDS community. That effort has come through the hard and tireless work by other groups on the margin.
These initial events of the nonresponsiveness that some white gay men faced from health officials were some of the first times that they ever experienced stigma or discrimination:

This experience would provide the first stage of politicization and consciousness-raising for many who, through either not openly identifying as gay or having the financial privilege to build a life (the areas where they live, the places where they work; the friends they have; and the establishments they frequent), they had been able to limit their encounters with a hostile, homophobic society. (Cohen 1993, 271)

The argument being made is not meant to minimize the intensity of the discrimination and stigma the white gay male community faced. Nor is it my intention to suggest a stagnant, homogeneous experience that all white gay men faced in confronting HIV/AIDS. It is, however, to suggest that because of their male identity, rarely did they suffer the burden of multiple stigmas. If any group was structurally in a “good” position to respond to HIV/AIDS, it was the white gay male community.

The other group we turn to look at through their experience of HIV/AIDS, stigma, and organizing are sex workers. Because of respondents’ background, one might assume that they would be caught in the locus of activity that marked several sex-worker organizations and spawned new ones regarding HIV/AIDS. This was not the case. They are stigmatized even within the sex workers’ movement because of drug use and their involvement primarily in a street-level sexwork.

Sex Work and Mobilization

The mobilization of sex workers around broad-based civil rights and human rights is not an entirely new phenomenon (Delacoste and Alexander 1987; Jenness 1993; Kempadoo and Doezema 1998; Pheterson 1996, 1989). In the 1970s in Europe, and then in the United States, sex workers collectively organized and engaged in social protest (Pheterson 1989; Jenness 1993). It was the first time that sex workers began to challenge dominant understandings of what the definition of prostitution was and assert the concept that sex workers had the right to organize on their own behalf. Prostitution itself was transformed into a new political subjectivity (S. Bell 1994).

Prostitute activists focused on the visibility of prostitution, the scapegoating of prostitutes as social pariahs, and the changing of laws that heavily favored men (Pheterson 1989). Other aspects of social protest often highlighted the brutality of the police, and struggled for a redefinition of prostitution (and other sexual services) as a type of work that should be governed under civil rather than criminal law (Pheterson 1989).
Shannon Bell describes the consequence of the various stages of prostitutes’ rights articulation:

These two historical processes, the first of which involves the extension of democratic equivalence to prostitute women, and the second of which arbitrarily refused women’s right to work as prostitutes, mobilized prostitutes as political subjects. It is the contradiction between the extension of democratic equivalence and the state’s campaign against prostitutes that produces the prostitute as a new political subject. (1994, 105)

For many women involved in these activities (particularly white women) of the seventies and eighties, prostitution was argued to be a part of one’s identity. The construction of prostitution shifted from that of social stigma and victimhood to a site of multiple (and sometimes contradictory) meanings that included pleasure, work, violence, autonomy, and self-hatred (see generally S. Bell 1994; Chapkis 1997). Prostitution from the vantage point of an affirmative identity is not currently accessible for many women, both active and nonactive sex workers.

In many of the early organizations questions about race, and specifically about women of color, were included in the analysis of harmful effects of racist structures in sex workers’ lives (Delacoste and Alexander 1987). The overall role(s) of women of color in prominent positions of the major organizations is somewhat unclear. In terms of leadership and central roles in these organizations, it would be fair to say that women of color, though involved, were not as visible as white women. Generally, urban women of color sex workers were not centrally organized or targeted. Women of color (who in some estimates make up the majority of street-level sex workers) have never been a visible force in the leadership. Drug-using women also had been relatively excluded from earlier movement organizing, and continue to occupy the bottom rung of the social ladder among sex workers (see Delacoste and Alexander 1987).

Because of the effects of race and class in many women’s lives (especially respondents) it is not possible or desirable for them to claim a space of subjective identity around prostitution or sex work or both. Very few women see themselves through the sole identity of prostitute. Some did have a sense of semiprofessional identity around sex work. However, the women could not easily incorporate the language of claiming one’s identity around prostitution, and then HIV/AIDS activism. The structural and cultural mechanisms and influence for such a movement were not in place. Although sex work has multiple and fluid meanings among the women, at the time they acquired the virus, few had a meta identity of sex worker to fall back on. Overall, urban women of color did not (and do not) often identify with earlier concepts of prostitutes’ rights. This does not mean that they do not understand or struggle with the concept of prostitution in their
communities. Rather, it means that the discursive space is different (and continues to be different) for these women (and others) than for primarily white and European women in the seventies, and who currently claim(ed) prostitution as an identity. Former women of color sex workers/lawbreakers are not in the same discursive category as are white women.

The terrain saw a discursive shift in prostitutes’ rights as well as material changes (see S. Bell 1994). In the 1980s, with the advent of the HIV/AIDS virus, prostitutes began again to be scapegoated as the infectious carriers of disease (Jenness 1993; Schneider and Stoller 1995; Stoller 1998). This was reminiscent of several earlier periods in American history. When this shift occurred, other types of organizing around civil rights and the continued extension of the rights of prostitutes as citizens began to wane. Consequently, as Jenness documents, sex workers and prostitute organizations and collectives had to fight on several different fronts at once as HIV/AIDS educators (S. Bell 1994; Jenness 1993; Stoller 1998). They did this for both their communities as well as for the often, more hostile wider community outside of prostitution.

Nancy Stoller discusses the new identity that competed for meanings with others, which shaped the category “prostitute”:

In organizations like Cal-PEP and its parent organization COYOTE (Call Off Your Old Tired Ethic), which were formed to advocate for and provide services to prostitutes, a new and anomalous role has been established—the prostitute as outreach worker or reformed native. . . . The AIDS crisis, in particular, has given new life to the redemptive identity of “ex-prostitute.” . . . In this context, sex workers may subversively accept the identity of disease carrier in order to secure funding, to force a place at the policy table, and to enhance recognition of their expertise in the public sexual realm. (1998, 84–85)

Women of my sample were not able to translate their knowledge into organizational resources solely as sex workers. Additionally, although there have been some halfhearted attempts to organize women on the street, there have been no truly successful efforts, and indeed Michigan is a state that has no active sex workers’ rights organizations. Additionally, in Detroit, when the earliest women had been diagnosed there existed virtually no literature on women and AIDS or general HIV/AIDS organizations. By examining some of the experiences of other groups, we can surmise that although other groups faced stigma, the degree to which they were able to organize was predicated on already established or emerging identities and collective resources.

What does a focus on intersectional experience tell us about the potential for political participation? First, it suggests that intersectional stigma can affect social and political participation. Using the concept of intersectional stigma, we can theorize the ways it affected how they perceived
themselves during their discovery of the HIV/AIDS virus, what resources they had available to them, their to routes to participation, and how they rerouted or diffused stigma. For people with intersectional experiences of stigma, participation requires an analysis of and redirection of stigma. All of these factors have been overlooked by traditional inquiries on participation. As noted previously, any of the stigmas discussed has the ability to overwhelm identity. Until stigma can be redirected, it will continue to affect the life chances and political opportunities people face.

**Coming Out of the Shadows: Stigmatized Women and Politics**

This book offers a political analysis of the participation of a select group of stigmatized HIV-positive women with an interpretative framework of intersectional stigma at the core. By understanding how stigma plays a defining role in the process of political consciousness, it offers different answers about what forms their participation takes and what barriers they face in staying active. Chapter 2 introduces the deep sample of women in the form of narrative bio-sketches. It provides an overview of important events regarding their drug use, sex work, and criminal activities prior to their acquisition of HIV.

Chapter 3 discusses the qualitative methods used to collect the total sample of respondents and the style of analysis. The pathway to participation for women with HIV/AIDS, which begins with the social conditions of the acquisition of the virus, is the subject of chapter 4. The process of life reconstruction is the main focus of chapter 5. It delves into the mechanism of life reconstruction that begins with recovery. Chapter 6 investigates the respondents’ struggles with facets of gender identity as an important component in their later political activity. It also discusses the tangible outcome of their sustained efforts—a persona, or public voice, and a defining role of what it means to be an HIV-positive woman. Chapter 7 illustrates the range of political activities in which the women are engaged, and how the concept of blended and overlapping roles is a useful heuristic tool to understand the meanings women give to the overlapping spheres of community, political, paid, and volunteer work. The last chapter, chapter 8, is the conclusion, advancing the claim that this work generates a new collective story of women who have become relevant social and political actors.