HIV-Positive Women and Political Advocacy in the United States

Senior Thesis
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Acronyms

AIDS – Acquired Immune Deficiency Syndrome
ACT UP – AIDS Coalition to Unleash Power
ASO – AIDS Service Organization
CDC – Centers for Disease Control
GMCH – Gay Men's Health Crisis
HAART – Highly Active Antiretroviral Treatment
HCSUS – HIV Cost and Services Utilization Study
HIV – Human Immuno-Deficiency Virus
LGBT – Lesbian, Gay, Bisexual, or Transgender
NEP – Needle Exchange Program
NIH – National Institutes of Health
NOW – National Organization for Women
PEPFAR – President’s Emergency Plan for AIDS Relief
PLWA – People Living With AIDS (as used in the RWCA)
PWA – People with AIDS
RWCA – Ryan White CARE (Comprehensive AIDS Resource Emergency) Act
TWC – The Women's Collective
WWA – Women with AIDS
Introduction

In light of World AIDS Day, there has been a great deal of publicity recently about HIV/AIDS, both in the U.S. and internationally. Additionally, The HIV/AIDS Administration (HAA) of Washington, DC released the first new report on HIV/AIDS in the District in several years. Contrary to the stereotype of HIV/AIDS as a gay, white male’s disease, the report reveals the great risk indicated for women, for people of color, and by mode of heterosexual transmission. In response to this epidemiological data, Sharon Hader, the new director of HAA, remarked that, “It blows the stereotype out of the water” (Levine 2007), indicating that it is becoming increasingly impossible to ignore the reality of these statistics.

The fact is, as I will explain in detail later in this paper, that this is not new information. Infection rates for women specifically have been rising steadily for a decade, along with the risk associated with heterosexual transmission. However, HIV/AIDS continues to be stereotyped as a disease that only affects certain risk groups, like gay men. This is not only incorrect, but also harmful in that it has caused policies to be skewed and resources to be inaccurately directed. The time has come for the stereotype to be blown out of the water once and for all.

In this paper, I work from the perspective that the best way for that change in thinking to occur is through political action on the part of the people who stand to suffer the most if policies and perspectives do not change. Many challenges stand in the way of such action and involvement, but it is in the interest of direct AIDS service organizations to work to help women all over the U.S. overcome those challenges and join their voices together to make demands about their health, education, and treatment.
Community Profile

I. History of HIV/AIDS in the USA

The AIDS epidemic officially began in the U.S. when it was diagnosed in a group of five homosexual men in Los Angeles in 1981. Doctors began calling the disease GRID, or Gay-Related Immune Deficiency. By 1982, it was widely recognized that homosexuals were not the only affected group. Hemophiliacs, injection drug users, and Haitian immigrants accounted for large proportions of new cases. Women that were diagnosed with HIV were primarily members of these three groups for several years, and there were few resources allocated to researching the ways in which HIV affects women specifically. Many years later, there was still very little known about sexual transmission to women. The majority of prevention information and research was aimed at men who have sex with men, or substances abusers.¹

In January 1988, Dr. Robert Gould published an article in Cosmo magazine that reinforced the general misinformation about HIV/AIDS. He stated that that women having normal heterosexual intercourse were not at risk for contracting HIV (ACT/UP NYC 1992). This statement caused outrage among members of the ACT UP/NYC group, and was found to be false in the proceeding years. In fact, 80% of the 9,908 newly diagnosed infections among women in 2006 were transmitted through heterosexual transmission (CDC 2007a).

In the late 1980s and early 1990s, infection rates among women began to rise dramatically. Between 1989 and 1990, the number of cases of AIDS in women rose by 29%, as opposed to 18% in males, and women accounted for 13% of all new AIDS cases (CDC 1990). By 2000, women accounted for 27% of all new AIDS cases (See Figure 1).

II. HIV/AIDS in Men and Women

Biologically and socially, HIV affects women differently than men in terms of their risk level and access to care. Biologically, a woman is significantly more likely than a man to contract HIV infection during vaginal intercourse (European Study Group 1992, Padian et al, 1991). This biological fact is compounded by the reality that women often are disadvantaged socially in sexual encounters and relationships. For instance, women, especially those living in poverty, have less control over their sexual relations (Beeker 1998). Further, some women face the threat of partner violence, which reduces women’s willingness to refuse sex or define the terms of those relations (Frieze and McHugh, 1992). In addition, gender inequality also means that women generally has less access to information, support, and services (Frieze and McHugh, 1992).

In addition, there is a discrepancy between men and women’s access to health care. A recent CDC study of more than 19,500 patients with HIV in 10 US cities reported that women were less likely than men to receive prescriptions for the most effective treatments for HIV infection (McNaghten, et al 2004). In consort with the previous findings, data shows that in the U.S. survival times for women are shorter than those for men, suggesting that women may have less access to life-prolonging care than men do (Bury 1992; ACT UP/NY 1992).
III. Demographics of Seropositivity² Among Women

Epidemiological studies show rising numbers of HIV/AIDS cases. Looking at the data about HIV and race, socio-economic status, age, and geography reveals alarming information and disparities about risk levels among certain populations.

Race

Black women account for 66% of new AIDS cases in the U.S., but only 12% of the U.S. population (See Figure 2). While mother-to-child transmission has been dramatically decreased due to antiretroviral treatments, the 2% risk of mother-to-child transmission overwhelming affects black Americans (Kaiser Family Foundation 2007). Among African American women in that age group, 25-44, HIV/AIDS is now the number 1 cause of death (CDC 2007).

Figure 2. Estimated AIDS Diagnoses and U.S. Female Population, by Race/Ethnicity, 2005

² The prevalence of HIV/AIDS is often discussed in terms of seropositivity, which simply refers to the existence of HIV antibodies in the blood. Unless specified as an AIDS case, being seropositive does not necessarily imply that the disease has progressed to the point of AIDS. The term seropositive can technically be used to describe the existence of any type of antibodies, although it is most commonly used to refer to HIV, and will always be used in such a context in this paper.
**Socio-Economic Status**

It is difficult to measure income or class of those infected by HIV on a national level, but the HIV Cost and Services Utilization Study (HCSUS) reported that two-thirds (64%) of women with HIV are living with annual incomes below $10,000, compared to 41% of their male counterparts (Bozzette 1998). The HCSUS also revealed that women with HIV are also less likely to receive care than men because they lack transportation (26% of women, compared to 12% of men), or because they were too sick to go to the doctor (23% of women, compared to 14% of men) (Shapiro 1999; Cunningham 1999).

Type of insurance can be used as a way of measuring socio-economic status and income as well. The HCSUS also reported that, of those receiving care for HIV, women are more likely than men (61% of women, compared to 39% of men) to be on Medicaid. Women are much less likely to be privately insured (14% of women, compared to 36% of men), and about as likely to be uninsured (21% of women, compared to 19% of men) (Bozzette 1998; Kaiser Family Foundation 2007).

It is likely that many of the issues associated with poverty may lead, directly or indirectly, to increased risk for HIV. These issues may include: limited access to high-quality health care; the exchange of sex for drugs, money, or to meet other needs; and higher levels of substance use can directly or indirectly increase HIV risk factors (Diaz 1994). A study of HIV transmission among black women in North Carolina found that women with a diagnosis of HIV infection were significantly more likely than women who were not infected to be unemployed; to have had more sex partners; to use crack/cocaine; to exchange sex for money, shelter, or drugs; or to receive public assistance (CDC 2005b). It should also be noted that it is difficult to separate risk enhancement based on poverty from that based on race, since nearly 1 in 4 African Americans and 1 in 5 Hispanics live in poverty (U.S Census Bureau 1999).
Age

The majority (71%) of new AIDS cases in women today are diagnosed in women aged 25-44. Although many of the infections could occur at younger ages (CDC HIV/AIDS Supplemental Report 2005). In the 13-19 age group, girls account for 43% of the total cases; and among those aged 20-24, women account for 28% (CDC Slide Set: Adolescents 2006). Experts fear that these statistics could be a harbinger of the trajectory of the epidemic of the risk posed to those outside of the traditional, identifiable risk groups – both women and youth (Kaiser Family Foundation 2007).

Geography

Considering the rates of AIDS by state, by far, the highest numbers of AIDS cases among women are reported in New York and Florida (See Figure 3).

**Figure 3. Number of Women/Girls Estimated to be Living with AIDS: Top 10 States, 2005**

<table>
<thead>
<tr>
<th>State</th>
<th>Number of Women/Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York</td>
<td>22,226</td>
</tr>
<tr>
<td>Florida</td>
<td>12,657</td>
</tr>
<tr>
<td>California</td>
<td>6,586</td>
</tr>
<tr>
<td>Texas</td>
<td>6,042</td>
</tr>
<tr>
<td>New Jersey</td>
<td>5,700</td>
</tr>
<tr>
<td>Maryland</td>
<td>4,591</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>4,321</td>
</tr>
<tr>
<td>Georgia</td>
<td>3,785</td>
</tr>
<tr>
<td>Illinois</td>
<td>3,144</td>
</tr>
<tr>
<td>Puerto Rico</td>
<td>3,075</td>
</tr>
</tbody>
</table>


An analysis of the case rates of AIDS among women, measured per 100,000, shows that six of the ten states with the highest per capita rates for women are in the South\(^3\). The District of Columbia tops the list, with 100 cases per 100,000 women, or 12 times the average national rate for cases among women (Kaiser Family Foundation 2007).

\(^3\) This statistic is different from what is listed in the chart. The chart show the numbers of cases in total, but this statistic refers to the rates of prevalence after adjusting for different population sizes.
Summary

In brief, women of color – especially black women – are more likely to be infected with HIV than their white counterparts. Also, women are infected at younger ages and women who are infected are poorer than their male counterparts. Finally, women in the South are more likely to be infected than other women, although numbers of cases are high in other places as well.

IV. Activism against HIV/AIDS in the U.S.

The gay community in the U.S. was the first to be affected by HIV/AIDS, and was also the quickest to respond. For reasons I will discuss later, the gay community already had a sense of collective identity that facilitated their response. The AIDS Coalition to Unleash Power (ACT UP) was founded in New York in 1987. This group made demands regarding the need for access to better drugs at cheaper prices, public education about AIDS, and the prohibition of AIDS-related discrimination. Starting in 1987, they took to the streets (Wall Street, in particular) in masse, holding provocative signs declaring, “SILENCE=DEATH.” Emblems like this one, held up by members of the gay community became, and to some degree still remain, the image of AIDS activism that is held in the mind’s eye of the public.

Through the end of the 1980s and the early 1990s, most of the women who were involved in AIDS activism fell into two camps, being either lesbians or privileged women. Because of the fundamental connections between the gay community and AIDS activism, some lesbians were involved in activism from the beginning (ACT UP 1992). They were more often make demands in solidarity with gay men than making separate arguments about the needs of lesbians with regard to HIV/AIDS. Furthermore, even among heterosexual women, the AIDS activists have not necessarily been representative of the women most at risk for HIV.
“Despite the fact that rates of seropositivity among Western women are highest among lower-class black or Latina women, such women are also the least visible in discourses on AIDS. Rather, it is the middle-class white women—those who are statistically less likely to contract HIV and thus somewhat atypical AIDS victims—who appear most frequently” (Sacks 1996).

One of the women most known for her activism about AIDS is Mary Fisher (see Figure 4), who delivered a famous speech at the 1992 Republican Convention. Regarding her own socio-economic status and identity, she said,

“Though I am white and a mother, I am one with a black infant struggling with tubes in a Philadelphia hospital. Though I am female and contracted this disease in marriage and enjoy the warm support of my family, I am one with the lonely gay man sheltering a flickering candle from the cold wind of his family’s rejection.”

Her voice was important in shifting national dialogue about who was at risk for HIV/AIDS, but the fact remains that her experiences were not necessarily fully representative of the epidemic.

**Figure 4. Photo of Mary Fisher, 1992 Republican Convention**

AIDS activists have had many successes including more federal funding for treatment programs, better drugs, improved comprehensive public education about the epidemic, more scientific and social research about the epidemic, and so on. I will discuss many of these successes as well various methods for AIDS activism in the literature review portion of this paper.

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V. Community Partner Organization

The Women’s Collective (TWC) is a non-profit organization in Washington, DC, led by women with HIV and their allies/advocates. The organization has been working for 15 years to serve the needs of HIV-positive women in Washington, DC and beyond. Their mission is “to meet the self-defined needs of women and their families living with and at risk for HIV/AIDS, reducing barriers to care and strengthening their network of support and services.” The advocacy department at TWC was established in the Spring of 2007, and is still in the early stages of development. The mission of the advocacy department is “to ensure that women living with HIV/AIDS or those who are at high-risk of contracting HIV/AIDS, are an integral part of national debates about issues that affect their lives.” It is crucial to the future development of this program that the staff and participants are able to identify and learn from their challenges and develop new approaches overcoming them. This project will aim to support the department and the participants in this goal.

\[http://www.womenscollective.org\]
Literature Review

In order to set a background for my findings, I will review several bodies of literature in this section. This investigation will be based on theory written about social movements, which can be defined as a purposeful and organized political challenge by a group or groups that is directed at changing the prevailing practices of “institutions, elites, authorities, or other groups” (Tarrow, 1991), and is particularly relevant to the case of grassroots activism. Social movements are composed of disparate individuals and groups who have come together to see themselves, and be perceived by others, as sharing a collective identity (Diani 1992). I will go on to describe social movements of the past as well as the main actions that would constitute a social movement in the case of HIV-positive women.

The literature in this paper will focus only on cases and conclusions made in the United States. Other nations and cultural traditions demonstrate different attitudes towards sexuality, risk indicators, political systems, and political histories that complicate the process of making useful comparisons to the U.S. Furthermore, it should be noted that there are clearly lines to be drawn within the U.S. population of HIV-positive women with regard to these and other issues, however the aim of this paper is not to analyze specific subgroups. For example, women with mental illnesses or who have used injection drugs deal with different challenges than women who are victims of domestic violence or women who are immigrants to the U.S. This research aims at building solidarity and a platform for advocacy among women as a larger whole.

I. Social Movement Theory and Empowerment

Taylor and Whittier (1992) described the basis of social movements as residing in interpersonal linkages and institutional bases. A movement develops by way of these interpersonal linkages, which make connections within a community and draws in other people to redefine the
boundaries of who can be involved in activism. As activism is particularly concerned with the concept of identity as the primary motivation for involvement, it must work within the cultural framework of the people that it attempts to reach, playing off of collective identity and taking cues from cultural beliefs and linguistic particularities.

In his book, *Activism Against AIDS*, Brett Stockdill (2003) focuses on the important aspects of AIDS activism: (1) individual empowerment, (2) collective consciousness, and (3) collective action. In the case of HIV-positive women, these outcomes may represent themselves as: first, individuals going to the doctor, becoming more involved in their own health care and case management, and trying to understand the law and policies in the U.S. about HIV; second, the increasing visibility of women who are not ashamed of their status and who are willing to share their stories and challenge stereotypes and oppressive ideology, and in such a situation, such stories will create a foundation for a group-based understanding of circumstances; and third, more women taking part in voting, grassroots organizing, peer or community education, and representation of HIV-positive women on committees and decision-making bodies.

These conceptions are different ways of categorizing many of the same components of a social movement. Perhaps the most useful conception of this is offered by Stockdill (2003) in a different section of the same book. According to him, social movement theory literature often explores the links between culture (identities, collective consciousness, and symbolic meanings) and structure (organizations, networks, institutions, policies and activities) as they pertain to collective action. I will examine identity, networks, organizations, and activities at a later point in this review, but I will now further explore the concept of the empowerment of women.
Empowerment of Women with AIDS

HIV/AIDS organizations in many places are already providing a long list of services to women, including case management, health care, and housing aid, and support groups. As critics have asserted, these activities are not sufficient to affect long-term change in policies, and in a sense, are only providing a Band-Aid solution to social ills that cannot be addressed through housing stipends and medications. However, these direct service activities can be conducted in such a way that encourages women to be involved in advocacy. For example, one of the primary goals of support groups is empowerment through camaraderie, and this sort of empowerment is fundamental in the creation an understanding of social ills. That being so, it is worthwhile to examine the history of thought regarding empowerment, which considered to be one element of a social movement. Although the concept of empowerment has a long history in the fields of public health and community psychology, it appears that there is not yet consensus over exactly what empowerment means or how it can be measured.

The very foundation of public health, since the mid-1800s, has been built on the twin ideas that environmental, cultural, and other community-based factors have a profound influence on health, and that the community itself is the best source of knowledge about what problems exist and what remedies will be effective. In the context of public health, empowerment has been defined as “a social-action process that promotes the participation of people, organizations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice” (Wallerstein 1992). The field of community psychology was built around the definition of empowerment as “the process by which people, organizations and communities gain mastery over their lives” (Rappaport 1984). Beeker (1998) defines a community empowerment intervention as a program that “seeks to affect community-wide change in health-related behaviors by organizing communities to define their health problems, to identify the
determinants of those problems, and to engage in effective individual and collective action to change those determinants.” This concept of gaining “mastery over their lives” through “collective action” addresses the needs of HIV-positive women to change their social status and take action to improve their health.

There are many elements that contribute to empowering people to be politically engaged. One such element is reported by Robert Putnam in *Making Democracy Work* (1993). Through a study of twenty regional governments in Italy, beginning in the 1970s, it was demonstrated that formal democratic participation must be paralleled by strong network of civic engagement such as neighborhood associations, cooperatives, and sports clubs, all characterized by intense horizontal interaction. In the case of HIV/AIDS, support groups and other ASO activities can be substituted for neighborhood organizations. Empowerment initiatives operate, as one outreach worker in Chicago said, “to help develop a sense of ‘entitlement’ among women with HIV and AIDS so that they were better able to demand housing, health care and so on” (Stockdill 2003). In other words, often consciousness raising must be complemented by a reinforcement of the participants’ sense of agency. Empowerment should not only be focused on the individual, but also the empowerment of an entire community and addressing the psychological effects of internalized oppression based on race, class, or sexual-orientation.

In her writing on community – as opposed to individual – empowerment, Beeker provides some guidelines that are useful in the specific case of laying the groundwork for political engagement. She states that empowerment interventions should have a focus on “capacity building,” which can be measured in terms of access to and effective use of financial and material resources, technical resources (like individual skills and organizational capacities) and social resources (such as community leaders, alliances with strong community-based institutions, coalitions of community organizations, and high levels of civic engagement, or citizen participation). The
goals of advocacy training would overlap with these empowerment goals to support women in developing the capacity to manage financial, technical, and social resources.

Although there is an enormous amount of literature on empowerment, this paper will focus on these two modes of empowerment: horizontal interactions, which are not necessarily politically-oriented, and activities that give women specific skills with regard to their ability to manage financial, technical, and social resources.

A. Examples of Social Movements

Because the rates of HIV/AIDS transmission to women are highest among African American women, there is a particular need to better understand how social movements and empowerment involving similar groups have functioned and to what extent they have been successful in achieving their goals. For this purpose, I will present the perspectives of several researchers on social movements about HIV/AIDS, as well as social movements that organized several disenfranchised groups. I will highlight some of the most unique and important aspects of each of these social movements and then connect these lessons to the topic of HIV-positive women, in order to provide a useful foundation for assessing that movement.

1. Populations Affected by HIV

This section will discuss three separate populations – homosexual men, drug users, and the “innocent victims” – that have developed social movements in order to voice their opinions and needs with regard to HIV policy.

Homosexual men

One of the earliest organization responses to the AIDS epidemic was in the Gay Men's Health Crisis (GMHC), founded in New York City in 1982, which was an organization primarily focused on
responding to the social and medical needs of AIDS patients. It was not until 1987 when the AIDS Coalition to Unleash Power (ACT UP) was founded in New York City that there was an organization that worked effectively to bring AIDS into the public eye as a political issue. It is important to note that there were AIDS activists before 1987 (including many individuals and those people involved in GMHC); however, ACT UP was the organization that attracted the most public attention and constituted the face of AIDS activism (Diedrich 2007). Although there were female members of ACT UP, Patrick Moore (2004) describes the culture of ACT UP as decidedly queer and “inclusive but intensely competitive, highly sexual, intelligent, and chaotic.”

There are many explanations as to how this movement achieved the success that it did. Tempalski et al. (2007) suggests that the original AIDS movement was successful for the following reasons: they challenged mainstream medical knowledge; the activists themselves embodied the face of the disease, and therefore spoke with a great deal of authority and contradicted the notion that their bodies served only a vectors of infection; and finally, the activists collaborated with medical researchers and professionals. Other researchers focus more on how the movement formed than what activists actually did. Gay organizations and community centers already existed in the United States prior to the AIDS epidemic, and were poised to take action based on a previously formed sense of collective identity. Gay activists were able to take advantage of new forms of technology that allowed them to use home video equipment to document their activities (Hilderbrand 2004). Gay activists also used many creative methods to convey their message, such as public art and theater (Hilderbrand 2004).

The homosexual movement was met with resistance. For example, in his book, The AIDS Cover Up?, Gene Antonio (1986) argued that prevention programs focused on AIDS awareness and safe sex methods were normalizing bad habits and supporting sexual activities that would lead to the self-extinction of mankind. He was concerned that the CDC seemed to be controlled by the
‘homosexual lobby,’ which, by promoting safe sex for everyone, was creating an aversion to heterosexual intercourse as well. Such literature embodied the challenge posed by the stigma surrounding homosexuality.

Despite this type of direct resistance, this movement has achieved a great deal of success in achieving its goals. AIDS activists brought about massive changes within the health care system by targeting researchers and drug companies directly to speed up drug trial, bring about pharmaceutical drug price reductions, and increase funding for research about AIDS (Hoffman 2003). Gregg Bordowitz, a long-time AIDS activist, said in an interview about ACT UP that "The biggest achievement [of the organization] was the idea that people with AIDS should be in control of the decisions that govern our treatment and cure. It’s the one thing I return to, that principle that the people with the disease should be at the center of a discussion about the disease. No more of this notion of patients being taken care of, that patients play an active role in their care" (Bordowitz 2002).

**Drug Users**

For injection drug users, one of the most important modes of HIV prevention is through needle exchange programs (NEPs). The first of these programs was started by a student at Yale University in 1986. As of November 2007, a total of 185 NEPs were operating in 36 states, the District of Columbia, and Puerto Rico (CDC 2007). The majority of the NEPs in the U.S. were initiated by local activists of community members and are still operated by non-governmental organizations (Tempalski et al., 2003; Bluthenthal 1998; Moseley 2007). The degree to which the impacted community was involved in advocacy varies greatly, but Bluthenthal (1998) observed that the success of the program in Oakland, California was largely due to the involvement of drug users themselves.
However, advocates of NEPs continue to face large challenges: in many cities in the U.S. it is illegal to buy syringes at all, in other places the local governments refuse to allow public funds to support NEPs, and the federal government prohibits the use of federal funds for NEPs (Strathdee 2003; CDC 2007).

It is not for lack of research or supportive evidence that these harm-reduction programs have been rejected or neglected at the governmental level. At least 8 major national reports have affirmed the efficacy of NEPs as a tool to prevent the spread of HIV/AIDS, while not increasing drug use (Buchanan 2003). The former Surgeon General represented the point of view of public health professionals when he stated the following: “After reviewing all of the research to date, the senior scientists of the Department and I have unanimously agreed that there is conclusive scientific evidence that syringe exchange programs, as part of a comprehensive HIV prevention strategy, are an effective public health intervention that reduces the transmission of HIV and does not encourage the use of illegal drugs” (Satcher 2000).

However, this movement has had scattered success all over the U.S for several reasons. First, on a national level, there has been some effort to organize activists, most notably through the North American Syringe Exchange Network, but the movement and most programs have not been planned according to a rational or cost-effective public health strategy (Tempalski et al 2007). Also, due to the common misconception that NEPs promote and increase drug use, public opinion of NEPs remains low, which has been reflected in government policies (Vernick et al 2003). Finally, while many NEPs have been started by members of the impacted communities, other were not, and the overall number of activists from within the community is low (Tempalski et al., 2003). Although few scholars have commented on this, it seems obvious that this could very well be because of the nature of drug use and the health and mental problems caused by drug use over long periods of time.
Hemophiliacs

Another set of voices that was raised up against HIV/AIDS have been those of the hemophiliacs, as well as those of anyone who contracted HIV through a blood transfusion. The literal poster-child for this movement was Ryan White, a white honor student with an innocent face from Kokomo, Indiana. He was 13 years old in 1984 when he was diagnosed with AIDS, and the next years of his life, until he died at age 18, were full of conflict and publicity. Out of fear and lack of knowledge about HIV, his community ostracized him and prohibited him from attending school, which inspired a nation-wide response in support of his cause.

White himself hit the nail on the head when he said, “I wasn't that different from everyone else. I wasn't gay; I wasn't into drugs. I was just another kid from Kokomo” (Richard 1999). The pictures published of him told the story of a boy who had never done anything “wrong” in his short life – a true victim (SerVaas 1988). Prior to the diagnosis of Ryan White and others like him, the epidemic had been constructed as a disease affecting people who engaged in perverted forms of sexual activity or in drug use; and in the minds of the American public, those individuals could not completely be absolved from blame for their infection. However in the case of Ryan White, it seemed very clear that the medical system in America – that caused his infection – had failed him in some way that he did not deserve, making it a tragedy that the same system was unable to heal him (Richard 1999).

Other similar figures shared some of the spotlight with White. Joshua Lunior and Ricky Ray, who were also young hemophiliacs diagnosed in the 1980s, suffered from a fear of stigma, but eventually became very public about their HIV status (Sternberg 2006). But rather than being particularly charismatic or motivating leaders, these young “victims” stood as symbols that the general public could relate to and find inspiration in. Thus began a movement to address the risk related to the purity of the nation’s blood supply.
Several celebrities took up this cause, most notably Elton John, who developed a relationship with the Ryan White and went on the found the Elton John HIV/AIDS Foundation (Armoudian 1997). Dr. Bruce Evatt, of the CDC, and the National Hemophilia Foundation were key players in promoting research and demanding funding to support programs that would protect the hemophiliac population (SerVaas 1988).

Not only did the American public see the tragedy of Ryan White’s situation, but it also became obvious that his family suffered with him. As he was often sick, his single mother was frequently unable to go to work. Clear from the prejudice and the contestable factors that were present in the case of many other HIV patients, it was clear that more must be done on the part of the government to provide support for HIV patients and their families (SerVaas 1988). From this understanding grew the general support for the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which provides funding to improve availability of care for low-income, uninsured and under-insured victims of AIDS and their families. This legislation was and continues to be absolutely the most important piece of AIDS legislation. It is paradoxical – but not surprising – that this legislation is named a boy that, as a hemophiliac, represents approximately 2.8% of the total cases of HIV reported in the U.S. between 1985 and 1992 (Franceschi 1995).

2. Disenfranchised Populations

Here I will look at some of the challenges faced by and the techniques used by populations that have been legally and socially marginalized, including African Americans (and the civil rights movement), sex workers, and the indigenous population in the U.S.
Civil Rights

The civil rights movement is arguably the most well-known and most successful social movement in the U.S. Among other successes, the civil rights movement was able to overthrow the Jim Crowe regime and establish equal civil rights for people of all races. This particular movement caused a paradigm shift in the ways in which scholars theorized about social movements. Following the civil rights movement, scholars no longer argued that social movements were spontaneous and unstructured; but rather, they began to theorize about the rational and institutionalized nature of social movements (Morris 1999).

The primary reasons for the success of the movement seem fairly obvious, being that it was a cause that affected a huge number of people, that the movement had charismatic leadership, and that many (although not all) of those leaders were dedicated to non-violent means for achieving their ultimate goals. Beyond these items, other scholars argue over the other factors that contributed to the success of the movement. One theory about the specific time in which this movement emerged has to do with the fact that the African-American population was moving around the U.S. at faster than previously observed rates and coming into contact with various ideas and people, and also that the college enrollment rates and levels of education among that community were higher than ever before (Lewis 1986). Peter Ling (2006) bring out the contradictions in the statements of other theorists, specifically Robert Putnam and Aldon Morris, who say, on one hand, that the 1960s witnessed a great decline of social capital in all parts of the U.S. and especially in the South (Putnam), and on the other hand, that the South possessed greater amount of social capital than other areas due to the prevalence of the African American church, which possessed a good deal of resources (Morris). In a sense, all of these arguments are true, but it is difficult to make generalized statements about a movement that was so broad-reaching.
Sex Workers

Sex workers in America are stigmatized, victim to violent treatment and poor working conditions, and at high-risk for STIs. While a clear mobilization of sex workers to call attention to their rights and needs does exist (exemplified by the organization Call Off Your Old Tired Ethics – COYOTE, the Sex Worker’s Art Show, and a number of authors who have written extensively on the topic), the vast majority of sex workers in the US are not involved with advocacy (Alexander 1996).

The literature suggests several explanations for this lack of advocacy. First, in the United States, all aspects of sex work are illegal. Sex workers are also stigmatized and scrutinized by the general public, and as such are often blamed for the circumstances in which they exist (Overall 1992). The legal and social status of sex workers plays an important role in pushing sex workers underground and preventing them from organizing. Also, sex work, not only sex trafficking, has long been associated with migration, serving as one adaptive strategy to cope with stress, dislocation, unemployment, and so on (Roberts 1992). Individuals who are physically on the move or in a transitional phase in their lives are not likely to be able to be involved in a social movement that involves networks on connections and the construction of official structures and organizations. Finally, “sex work is experienced as an integral part of many women’s and men’s lives around the world, and not necessarily as the sole defining activity around which their sense of self or identity is shaped” (Kempadoo 1998). Sex workers work in a variety of environments for a long list of reasons, have a wide range of experiences while engaging in sex work, and may not necessarily

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6 http://www.coyotela.org/what_is.html
7 http://www.sexworkersonline.org/home.html
8 Among others, these writers include Kamala Kempadoo, Joanna Brewis, Priscilla Alexander, Gayle Rubins, Kate Millet, and Melissa Farley.
9 Sex trafficking, or the forced movement of people – usually women – for the purposes of sex slavery or another other form of forced prostitution, is obviously very closely tied to migration since movement is a key element of its definition. However, the point should be made that other forms of prostitution that are not inside the realm of slavery also often imply migration.
consider themselves to be sex workers even when they exchange sex for money. All of these factors make the construction of a collective identity on which to base a social movement very problematic.

**Indigenous People**

Throughout the history of the United States, the indigenous population has been arguably the most marginalized and victimized population. Through grassroots activism, they have made significantly advanced their interests by influencing policy. These advances include gaining the right of universal franchise in 1948 and other advances related to conflicts over land ownership. However, this movement has faced serious challenges as well.

As in the case of prostitution, one of the most problematic aspects of creating an indigenous social movement has been due to the difficulty of creating a collective identity. There exist many separate tribal, ethnic, and cultural identities within the broader category of being of indigenous descent. Furthermore, some indigenous people are scattered all over the U.S., living in urban areas, reservations, or other rural areas (Wilkes 2006). The result of this situation is that often indigenous activism has been focused on local issues and particular cultural conflicts.

One aspect of the indigenous movement that has been particularly successful has been their efforts to connect with other social movements, particularly the environmental movement (Bullard and Johnson 2000). Through establishing connections with groups whose interests overlapped with theirs, they magnified their voice and effectively connected themselves to new resources.

**3. Women**

This section will describe the mobilization of two female groups of activists around issues of women’s health. Both the breast cancer movement and the pro-choice movement have been able to
call large groups of women into action to demand policies that respect the needs and lives of women.

Breast Cancer

The wives of presidents and vice presidents, actresses, and other high-profile, respected women have gone public about their struggles with breast cancer. While it is an issue that some women are reluctant to speak about, the nature of the disease is very different from that of AIDS because there is no blame placed on the victim of cancer (Boehmer 2000).

Even so, it would be inaccurate to say that breast cancer affects all types of women equally. The prevalence of breast cancer among lesbian women is about three times higher than that in heterosexual women, which is likely a result of the fact that lesbians generally smoke more, are more likely to abuse alcohol, have high body mass index, and are less likely to give birth (Boehmer 2000). Also, white women are much more likely to get breast cancer than any other group of non-white women; but African American women are more likely to die from breast cancer than white women (Boehmer 2000). That being so, women who identify as a part of a group that is at-risk have been more likely than other women to take part in activism to demand that their needs, with regard to breast cancer, are addressed. If there were no risk groups, then these women would be less able to identify specific needs in the context of a group or social movement. At the same time, since socio-economic factors like poverty and lack of education are not risk factors for developing breast cancer, the women who suffer are more likely (than those who contract HIV/AIDS) to have the resources to take part in effective activism. In other words, the risk groups that have developed do not correspond to factors that would complicate activism.

With what looks like an elite group of activists (compared to those most affected by HIV), breast cancer activists have been very successful in forcing the medical and governmental communities to participate in discussion and confrontation, and listen to testimony concerning the
need for more research about the causes of and best treatment for breast cancer (Anglin 1997).

Their financial resources and existing social capital have been important in allowing them to bring professionals to the table.

Some authors have suggested that the breast cancer movement has been too medicalized in focusing on raising awareness, providing support systems, and raising money for medical research, instead of giving much-needed attention to the structural issues concerning access to health care and environmental health (Moffett 2003). Aside from the practical advantages of this approach, Moffett also suggest that such an approach would allow breast cancer activists to forge bonds of solidarity with other social justice movements.

**Pro-choice Movement**

The movement to legalize abortion emerged in the 1960s, and had its greatest success in the Roe v. Wade Supreme Court case in 1973. There were four three elements of this movement that contributed significantly to its success: professional and organizational bases, grassroots action, and connections to other movements.

The fact that an important key to the success of the pro-choice movement was the ability to garner organizational and grassroots support is not necessarily unique to this movement. Medical and legal interest groups teamed with family-planning organizations to provide convincing research and a professional perspective, and waves of protest (particularly those instigated by young women, who found themselves in an era of expanded college enrollment and sexual revolution) provided the grassroots energy that fueled media attention (Staggenborg 1991). What is relevant about this movement to the case of HIV-positive women is the African American, female bloc of supporters. African American women have a long history of advocacy regarding contraception, and have been more likely to use methods of fertility control than their white counterparts (Ross 1998).
Furthermore, when abortion was illegal, septic abortions was one of the main killers of African American women. Family planning was an issue that affected all African American women, and in arguing for the right to make choices about their reproductive health, African American women mobilized in masse, and aggressively confronted their racist and sexist critics (Ross 1998).

Single-issue abortion activists were able to align themselves with the re-emerging feminist movement during the 1960s (Staggenborg 1991). This was not necessarily an easy task, because the abortion issue was controversial and feminist organizations were reluctant to support a cause that could splinter their members or damage their credibility. In the case, of the National Organization for Women (NOW), one of the major feminist organizations, personal connections between the director of the organization and abortion activists were what finally brought organizational support from NOW. Other groups, like population organizations including the Association for Voluntary Sterilization (AVS) and Zero Population Growth (ZPG) were fairly quick to expose themselves as pro-choice.

### IV. Comparisons

So what do all of these social movements have to do with women and HIV? The successes and struggles of these various groups of people organizing around an issue represent many of the same characteristics that women have and will face in their efforts to advocate for better HIV policies. It is helpful to position the constituency of this movement among many others in order to understand what is realistic, and what is to be avoided or expected.

As Morris (1999) showed about the civil rights movement, the most effectively social movements are the ones that take place through an organized and institutionalized effort. There are several other factors in other social movements that HIV-positive women can easily capitalize on. The ability of the homosexual men with HIV to represent themselves and speak with personal
authority and conviction on the issue, as well as the way in which their advocacy efforts worked against the notion that their bodies were solely vectors of disease, are both factors of success that women with HIV can easily take advantage of. Also connecting with other social movements and aligning their views in a larger ideological sense with others in that way that the indigenous people and pro-choice activists have done is a way that women can further their own cause. On the other side of that coin is the sex workers movement, which has been unable to avoid conflict with feminist movement.

However, some of the successes of other movements were based on factors that women with HIV cannot generally reproduce. The absence of these factors can often be scene as a challenge. One of the most important indicators of success has been the ability to establish a sense of collective identity. Prior to the outbreak of HIV, homosexual men in American had already organized around issues of sexuality and gender norms. When HIV began to affect their community, they were, in large part, already a cohesive community with personal and organizational linkages. On the other hand, one of the main challenges that the indigenous movement has faced has been reconciling the ethnic, linguistic, and cultural differences among the various indigenous identities. In other cases, the formation of identity was hindered by the presence of a stigma surrounding that identity. This has been the case with drug users and sex workers, while the innocent victims of HIV and of breast cancer were able to construct identities free of negative stigma. By analyzing these other movements, the importance of forming a group identity and combating negative stigma become apparent.

Another success factor, which seems obvious but is not as often discussed, that women with HIV cannot necessarily reproduce is the relative affluence and access to resources that the homosexual men's AIDS movement and the breast cancer movement were able to garner and use. The breast cancer movement specifically benefited from having actresses and the wives of respected
government officials as spokespeople from within the community of the affected. At the same time, as Ling (2006) said of the civil rights movement, it is important to value different kinds of social capital possess within various groups. In the case of HIV-positive women, there may be some undervalued asset lying in women's connections with each other through church communities or even a neighborhood beauty saloon.

B. Social Movements and HIV-Positive Women

These examples of social movements show that success and change are possible, if not overall, then over specific points of argument. The history of social movements affecting health and the provision of health care can be traced back much farther than any of the examples discussed here. This long history provides a great deal of material that can be used to assess and redirect the efforts of HIV-positive women.

As is the case with some of these examples, the potential of this movement in question has not yet been met due to several challenges. In the next sections I will look more closely at what the goals of this movement should be, as well as the specific challenges that is has or will face.

II. Goals of a Movement for Women with HIV/AIDS

In assessments of HIV/AIDS organizations, some scholars express concern that many organizations aim too narrowly to address the health-specific attitudes and competencies of individual members or program participants, without addressing cultural, structural, or other conditions that increase the vulnerability of women (Wingood and DiClemente, 1996). The HIV epidemic has magnified social inequalities in a very political way that ASOs (AIDS Service Organizations) cannot neglect to acknowledge. Organizations must not only provide health information and referrals for health-related services. In addition to these services, HIV
organizations should also create specific programs that increase awareness of the linkages between individual circumstances and community issues and work for sweeping changes (Beeker 1998; Robertson and Minkler 1994; Zimmerman 1995; Israel et al. 1994). This section will look at some of the specific issues that HIV-positive women should address through advocacy. I have divided these issues into two categories: prevention of HIV and the care for and treatment of HIV-positive women.

A. Prevention

An analysis of epidemiological trends of HIV shows that prevention efforts have failed to address the needs of women\(^\text{10}\). Women, both seropositive and seronegative, must demand that prevention programs address their practical needs as well as their structural disadvantages. Specifically, such programs must address women’s lack of control over their sexual health, the need for prevention messages geared towards women, and the need for more clinical research about women’s health issues.

For economic and social reasons women are often unable to gain complete control over their own sexual health. Women are more likely than men to be economically dependent on their partners (Brines 1994). This has to do with the gender wage gap, which indicates that women sometimes get paid less to do the same jobs, and with women’s role in completing informal work, like child care and housekeeping, which is not compensated for financially. Also, the social status of women in our society is manifest in other realities, such as violence against women and the different conceptions of male and female sexuality. In a survey of 8,000 women conducted by the Centers for Disease Control, 52% of them reported being victim to sexual assault during their lives (Tjaden 1998). Finally, sex and sexual activity are often conceptualized differently for men and women. As

\(^{10}\) See pages 6 – 9 of this paper.
such, as Patton explains below, the ways in which we think about the female role in sex makes it difficult to understand the risk carried by women.

“Sex is implicitly reconstituted as a man’s right and a woman’s obligation, with women responsible both for protecting men from disease [HIV] and for avoiding the consequences of transmission to a man’s child. From the ‘active,’ male perspective, right is equated with women, not with particular heterosexual practices. From the woman’s perspective, a husband or boyfriend may be at risk from someone else (a needle-sharing partner, a ‘homosexual’ partner or a ‘vagina’), and her child might be at risk from her (‘uterus’), but the twist in the logic of safe sex which encourages heterosexuals to view unpaid intercourse as ‘safe’ makes it difficult for a woman to perceive herself as at risk.” (Patton 1993)

It is not within the scope of this paper to fully discuss the ways in which women are lacking in terms of their power over their own reproductive health, but these are the issues that have been addressed to some extent by the feminist movement. Information about the generally accepted goals for women’s empowerment and rights is documented by the United Nations’ Population Fund11.

Prevention campaigns must have messages that are specially formulated to target women and answer to their needs. Cash (1996) argues that while educational messages about AIDS have been broadcast on television and printed in newspapers and magazines, such campaigns have not been proven to be very effective. To the contrary, mass campaigns can leave people confused about the actual modes of transmission of the disease or how to reduce risk. Instead, the standard messages of a campaign against AIDS, minimizing numbers of partners, using condoms, and treating other STIs, should be reformulated by women and for women. As Cash explains, to promote refraining from multiple partners often perpetuates that stereotype of AIDS as a disease of promiscuity and does not address women’s unique economic situations; to provide education on how to use condoms is irrelevant without condom negotiation skills; and to advocate for the treatment of STIs is unproductive without addressing the need for more accessible care and breaking apart the

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shameful stigma attached to STIs. There are more complicated issues to address with regard to women’s negotiation of safe sex. Since ceasing to use condoms in a heterosexual relationship is usually seen as a representation of trust, the opposite is also true in that demanding condom use in a long-term relationship is often seen as an accusation or confession (Gallois et al. 1990). Prevention programs should teach women how to deal with such a reality.

From the perspective of long-term prevention, there is a need for more clinical research on products and problems that affect women specifically. Family planners report that the most effective forms of pregnancy prevention have been those that are controlled by women, and as such, there should be more attention given to the forms of HIV prevention that can also be controlled by women (Stein 1990). Microbicides are one of the most important such form of prevention, which would be produced as creams or gels that women could apply vaginally to prevent the transmission of HIV. It is estimated that even if vaginal microbicides are only 60% effective and only used by 20% of women, in half of the sex acts where condoms were not used, they could prevent 2.5 million cases of HIV worldwide over a period of 3 years (GCM 2007). As microbicides would be a public health good and would be yield a large profit, pharmaceutical companies have failed to invest in their development. For every dollar that is invested in research related to HIV, only three cents goes toward researching microbicides (GCM 2007). Women must become more involved in voicing the need for more funding to find a microbicide that works.
B. Care and Treatment

Lack Professional Medical Attention to Women’s Experiences with HIV

In addition to the other barriers discussed in this paper that women face in receiving good health care, including financial barriers and the obligation to care for other people, among other reason, women also face the problem that many doctors are not knowledgeable about how HIV affects women differently from men. For example, women are less likely to participate in clinical drug trials and more likely to enter treatment further along in the course of the illness than men (Williams et al. 1997). Also, over half of the HIV-positive women surveyed who were or had been pregnant had not discussed with their health care provider how HIV might affect them differently as women or which HIV treatments were most appropriate for pregnancy (AIDS Weekly 2007). Also, sometimes female patients receive different care from men. It was found that in the late 1990s, HAART therapy\(^\text{12}\), the best and most advanced HIV treatment technology diffused more slowly to HIV-positive females than to other groups\(^\text{13}\) (Eisenman 2007). Women must argue for doctors and other health care providers to receive better training regarding how HIV affects women in different ways.

Necessity of Care for the Family

The HIV Cost and Services Utilization Study (HCSUS) found that 76% of women receiving care for HIV had children under the age of 18 in their homes, with the average fertility rate for HIV-positive women being 2.6 children per woman (Schuster 2000). Most women who contract HIV are in their reproductive years, and often are the primary caregivers for their children (CDC, 1999; 1999; 2000).

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\(^{12}\) Highly Active Antiretroviral Treatment (HAART) refers to a class of drugs that attacks HIV at the retrovirus stage of its lifecycle. HAART consists of a multi-drug therapy plan. These drugs were developed in the late 1980s and NIH recommends this form of treatment for all AIDS patients today. Drug resistance is easily formed and side effects can be debilitating.

\(^{13}\) This study acknowledged that one reason for this could be the lower average education levels and incomes of HIV-positive women, but concluded that the gender issues did produce a significant difference.
Murphy, Marelich, & Hoffman, 2002; Winstead et al., 2002). Women, generally speaking, are more likely than men to be caregivers for their children, spouses, friends, and elderly family members (Baines, Evans, and Neysmith 1991). Women with HIV are often faced with the challenge of coping with their own illness, while they care for chronically ill spouses and children. Many mothers are so involved with the care of their children that it is to the detriment of their own health (Sunderland and Holman 1993). Also women whose children became infected perinatally may experience intense feelings of guilt (Campbell 1999). These unique issues must be addressed in policy and in practice.

One study found that the care of a mother and her children, all with HIV, may require visits to 12 to 16 different agencies (Cohen and Kelly 1995). Family-centered care would mean that medical and other service appointments of mothers and children would be linked, and service provision would ensure that the interests of the mothers and children are not in conflict, economically or in terms of time (Kurth 1993). Furthermore, women with children often require transportation, day care, or home care (Holzemer, Rotherberg, and Fish 1995).

### III. Methods of Advocacy

Political involvement can be defined in a broad sense, to include the totality of “those activities of citizens that attempt to influence the structure of government, the selection of government authorities, or the policies of government” (Conway 2000). Whereas conventional thought on political participation included only such activities as voting, membership in political parties, and lobbying, over the last thirty years it has acquired a spectrum of meanings and a diversity of practices. Now political participation can refer to anything from community participation, to citizen engagement in policy formation, or any mode of action through which citizens can hold governments responsible for ‘good governance’ (Gaventa and Valderrama 1999).
Broadening the scope of political participation beyond voting, membership in political parties, and lobbying, not only includes other forms of activity, but also shows important differences in gender difference in political participation.

**Figure 5. Political Participation by Gender**

As seen above, in *The Private Roots of Public Action*, Nancy Burns (2001) broadens the scope of what most scholars look at as political participation to include – not only voting and other electoral activities – but also grassroots activity and protests in her analysis of the gender gap in political involvement. Burns uses the Citizen Participation survey to look at other activities, and by doing so, she acknowledges a more nuanced perspective on gendered political participation. In addition to the

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14 Burns comments that the focus of most scholars on electoral participation as equivalent to political participation is very likely because the best survey data (the biennial American National Election Study) supports this definition of political participation.
data she found that is seen in the figure, she also found that women are more likely to dedicate time
to a campaign or organization than men, but less likely to donate money or be officially affiliated
with a political group.

As Burns demonstrates, it can be very important to breakdown the definition of political
participation into certain kinds of activities. I will divide political involvement into two separate
categories, including those activities that are inwardly focused on the development of the movement
itself, and those that focus on making change outside of the movement, pushing it forward, and
aiming to affect policies directly. For practical purposes, I will refer to these activities as direct or
indirect.

A. Direct

Direct advocacy takes the form of voting, testifying before decision-making bodies,
lobbying, and serving in positions on policy-forming committees. The audience for these activities
is usually outside of group of HIV-positive women and has some power over the policy-making
process.

1. Voting

Although American women got the constitutional right to vote in 1920, voter turnout for
women did not reach that of men until the 1980 presidential election (Conway 2000). Today,
women are more likely to vote than men – 65% of women vote, compared to 62% of men (Holder
2006). However, many of the factors that put people at risk for contracting HIV make them less
likely to vote. Risk for infection can be tied to many factors including race, socio-economic status,
age, and geography. In short, women of color – especially black women – are more likely to be
infected with HIV than their white counterparts. Also, women are infected at younger ages and
women who are infected are poorer than their male counterparts. Finally, women in the South are
more likely to be infected than other women. As seen in Figure 6, these same factors are indicators for voting, and the very individuals that are in high risk categories for HIV infection are the least likely to vote, and therefore are losing this basic opportunity to voice their opinions.

Figure 6. Rates of Voting and Registration by Selected Characteristics, 2004 Presidential Election

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent Registered</th>
<th>Percent Voted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population eligible to vote</td>
<td>72.1%</td>
<td>63.8%</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>70.5%</td>
<td>62.1%</td>
</tr>
<tr>
<td>Women</td>
<td>73.6%</td>
<td>65.4%</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non Hispanic</td>
<td>75.1%</td>
<td>67.2%</td>
</tr>
<tr>
<td>Black</td>
<td>68.7%</td>
<td>60.0%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>57.9%</td>
<td>47.2%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 - 24 years</td>
<td>57.6%</td>
<td>46.7%</td>
</tr>
<tr>
<td>25 - 34 years</td>
<td>66.0%</td>
<td>55.7%</td>
</tr>
<tr>
<td>35 - 44 years</td>
<td>72.1%</td>
<td>64.0%</td>
</tr>
<tr>
<td>45 - 54 years</td>
<td>75.5%</td>
<td>68.7%</td>
</tr>
<tr>
<td>55 years and older</td>
<td>79.1%</td>
<td>71.8%</td>
</tr>
<tr>
<td>Annual Family Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>61.0%</td>
<td>48.3%</td>
</tr>
<tr>
<td>$20,000 to $29,999</td>
<td>68.8%</td>
<td>58.4%</td>
</tr>
<tr>
<td>$30,000 to $39,999</td>
<td>71.9%</td>
<td>62.1%</td>
</tr>
<tr>
<td>$40,000 to $49,999</td>
<td>76.8%</td>
<td>68.5%</td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>80.2%</td>
<td>72.2%</td>
</tr>
<tr>
<td>$75,000 to $99,999</td>
<td>83.4%</td>
<td>77.9%</td>
</tr>
<tr>
<td>$100,000 and over</td>
<td>85.9%</td>
<td>81.3%</td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwest</td>
<td>75.9%</td>
<td>67.8%</td>
</tr>
<tr>
<td>Northeast</td>
<td>71.4%</td>
<td>64.1%</td>
</tr>
<tr>
<td>West</td>
<td>70.7%</td>
<td>64.0%</td>
</tr>
<tr>
<td>South</td>
<td>70.8%</td>
<td>61.0%</td>
</tr>
</tbody>
</table>

2. Acting as Spokespersons

Here I wish to look at the spaces in which women can become spokespeople for other women with HIV, directing their arguments at policy makers themselves. While there are some more elite forms of representation, I wish to focus on the ones that any woman can theoretically participate in, including testifying before decision-making bodies, lobbying, and serving on policy-forming committees.

Although the concept of citizen or civil society participation in governance is central to democracy itself, "the challenge of building democratic polities where all can realize their rights and claim their citizenship is one of the greatest of our age" (Cornwell and Coelho 2004). For the "participatory sphere" of governance to be effective, it is not sufficient for the government to extend an invitation for community participation in policy planning. The possibility that the participatory sphere may be used by administrations for therapeutic or rubber-stamping purposes is great (Arnstein 1971). Instead, the types of structures which invite or allow participation, as well as the requirements for success, must be analyzed.

One way that any American can theoretically as a spokesperson is by contacting their representatives in the government and lobbying for their cause. HIV-positive women can and should lobby for increased funding for culturally specific prevention programs that target vulnerable groups, for the promotion of the civil liberties of persons with HIV, for assistance programs with qualifications and guidelines that are sensitive to women’s experiences, and for policies that support families (Perry 2003). Lobbying requires a fairly high level of knowledge about specific policies and legislation and, in many cases, an organized effort by many constituents. In order to achieve such conditions, in the case of HIV-positive women and provided that the barriers discuss in this
literature review exist, lobbying must often be coordinated by some NGO or other community-based organizations.

Another way that women can be spokespersons is by testifying before or sitting as a member of a policy planning committee. From its inception, the Ryan White CARE Act has included guidelines stating that community involvement in policy planning is key:

“The CARE Act stresses the role of local planning and decision making—with broad community involvement—to determine how to best meet HIV/AIDS care needs. This requires assessing the shifting demographics of new HIV/AIDS cases and revising care systems (e.g., capacity development to expand available services) to meet the needs of emerging communities and populations. A priority focus is on meeting the needs of traditionally underserved populations hardest hit by the epidemic, particularly PLWH who know their HIV status and are not in care. This entails outreach, early intervention services (EIS), and other needed services to ensure that clients receive primary health care and supportive services—directly or though appropriate linkages.”

In this spirit, Ryan White Planning Councils have been organized to encourage community involvement. Policies and procedures for these committees are different in every city and need to be evaluated more closely with regard to how women learn about them and how many women actually attend and participate in the meetings.

B. Indirect

Indirect activities are the ones that are focused within the community of women affected by HIV, taking the form of peer education and mentorship programs, prevention programs, and social networking. While these activities do not directly affect policy, they help to foster the development of a social movement as well as the development of the skills needed to affect policy.

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15 This description can be found at the HIV/AIDS Bureau website at: [http://hab.hrsa.gov/tools/title1/t1SecVChap2.htm](http://hab.hrsa.gov/tools/title1/t1SecVChap2.htm). (Text copied on December 2, 2007)
1. Peer Education and Mentorship

The primary type of program that has been established to support peer education and mentorship has been support groups. The founder of one support group for women with AIDS noted, “For some women, HIV is the first major disaster in their lives. For many more, AIDS is just one more problem on top of many others” (Farmer 1996). It is for this reason that support groups are one of the most common forms of service provided to AIDS patients through ASOs, aside from physical treatment: to help women (and other patients) address their questions and concerns that are not necessarily inside the medical realm. Although support groups are often effective and helpful, there is a need for support groups that more effectively address the needs of certain populations. Racial, ethnic and class differences can keep poor women from participating in support groups (Springer 1992), and compared to middle-class women, poor women do not always gain as much from “talking it out” endlessly and may not find support groups to be particularly. In order to make support groups more effective for various types of participants, there must be support groups available that are run by individuals who can make the participants feel comfortable. Often the best strategy for ensuring this is to have support groups operated by “peers,” or individuals with whom the participants have a great deal in common.

2. Involvement in Prevention Programs

As I explained previously, women have special needs with regard to what should be covered and how it should be presented in a comprehensive HIV prevention program. As such, other women are the most qualified to plan and present prevention material to other women.

Through her research, Cash (1996) developed a lost of content areas to be included in an STI/AIDS prevention program: AIDS and its transmission, STIs and their transmission, acquiring and using condoms, sexuality and mental health, reproductive health and family planning,
communication and information sharing, partner negotiation, identifying risk behavior, one’s health and the health of others, right to health education. These educational pieces not only serve the recipients of the information, but also reinforce the ability of the educators to speak about these issues. Furthermore, involvement in prevention activities helps to present activists as role models and to encourage the formation of networks of inter-personal relationships.

3. Networks

While building networks is not an inherently political activity, in the case of HIV/AIDS, the ability to create and maintains personal and professional relationships with people who have similar interests is a prerequisite to many other forms of political engagement. This is not necessarily true for voting; and while voting is not an insignificant act, in the case of HIV/AIDS, more action is needed. I am including networking as a form of political involvement not only because social movements require it, but also because working to connect people in a way that encourages them to see themselves as part of a network with a collective identity is a political act in itself. It is this capacity of social networks that Stockdill referred to in his third action of a social movement: creating concrete ties with the affected communities. Furthermore, in a 1992 American study of the Cross National Election Project, researchers found that politically-relevant social capital (that is, social capital that facilitates political engagement) is generated in personal networks; or, in other words, that increasing levels interconnectedness in social networks enhances the likelihood that a citizen will be engaged in politics (Lake 1998).

One of the goals of network analysis literature is to understand how social supports and social capital influence health (Luke 2007; Faber 2002; Borgatti 2003). Within this literature, social support can be measured by evaluating size of friend group, regular contact with family members and friends, and self-reported quality of social support received from others (Lin 1999). Social
capital, on the other hand, refers to how social relationships increase an individual’s access to resources (Borgatti 2003; Kawachi 1999; Sampson 1997). Case studies that have evaluated social networks and social capital as well as mental and physical health report that involvement in such networks can increase mental health and self-confidence, but not necessarily physical health (Wright 1995; Ziersch 2005). At the same time, improved mental health and increased access to resources can have an indirectly positive effect on physical health.

A study of the social networks for HIV-positive people in the U.S. documents that, compared to HIV-negative people, those who have HIV have smaller social networks and tend to share less personal information with those around them (Shelley 1995). It is difficult to conclusively determine whether this is due to self-isolation or actual discrimination by others, but the implications are clear: with a smaller social network that provides less substantial social support, HIV-positive people often do not have access to the confidence-building aspects of a social network or the opportunity to make associations between their own experiences and the experiences of others as they related to social and political issues.

C. Role of the AIDS Service Organization (ASO)

Given the information provided in this literature about women, HIV, and social movements, I will be making suggestions about the ways in which ASOs can most effectively promote political involvement among women. In order to do so, I will draw from Sara Evans’ (1979) work in analyzing the women’s liberation movement. She laid out five "essential preconditions for an insurgent collective identity":

1) *social spaces* within which members of an oppressed group can develop an independent sense of worth in contrast to their received definitions as second class or inferior citizens;
2) *role models* of people breaking out of patterns of passivity;
3) an *ideology* that can explain the course of oppression, justify revolt, and provide a vision of a qualitatively different future;
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4) a threat to the new found sense of self that forces a confrontation with the inherited cultural definitions—in other words, it becomes impossible for the individual to "make it on her own" and escape the boundaries of the oppressed group; and finally

5) a communication or friendship network through which a new interpretation can spread, activating the insurgent consciousness into a social movement

IV. Challenges to Advocacy

It is important to separate out the kinds of obstacles that women must overcome to become involved in advocacy. In the section below I will elaborate on the challenges posed by health, stigma, family considerations, financial concerns, unfamiliarity with political process, and lack of education of general skills.

A. Health

The physical challenges of coping with HIV and the struggles that individuals face in maneuvering a complicated health care system to receive access to medication and other health care services require investments of significant time and energy, and can therefore be barriers to political activism. Every person who is HIV-positive faces significant challenges, but it is also well-documented that there exist damaging inequalities in health and health care for women in the U.S. (Ratcliff 2002; Vigen 2006; Schulz 2006). The Kaiser Foundation brought together focus groups of women living in poverty with HIV in cities all over the US to discuss issues related to their ability to receive health care for their disease. The report from this study (Lake, Snell, Perry & Associates, Inc. 2003) documented several barriers to care for women with HIV. Women are usually diagnosed later because women are less likely to be seen as at-risk. Women who are privately insured (as opposed to using Medicaid) report having more negative experiences with trying to maneuver the health care system. The 20% of women with HIV that do not have health insurance faced nearly insurmountable challenges in receiving care. Many women reported having doctors who were not experienced with treating HIV in women and were not aware of how symptoms can be manifest
different in women. Women reported missing doctor’s appointments because of work, child care, or transportation, and having trouble sticking to strict drug regimens. Finally, children figure prominently in the healthcare choices of these women, and the family responsibilities of the women complicate their pursuit of care. In such a situation, it is obvious that health care and health-related problems present a major challenge for women trying to investing their time and energy in advocacy, which does not present immediate rewards.

**B. Stigma and Reluctance to Disclose Status**

Generally speaking, being stigmatized is a process by which individuals with devalued physical, behavioral, or medical attributes experience prejudice, discriminations, stereotyping, and exclusion (Bunn 2007; Dovidio, Major, & Crocker, 2000). It is well documented that HIV is a much stigmatized disease, as a result of its epidemiological history and a lack of knowledge about the facts of this disease. In order to address this issue, the HIV Stigma Scale was developed (Berger, et al., 2001), and has since been revised (Bunn, J. Y., et al. 2007). This scale measures stigma based on measurements of Enacted Stigma, Disclosure Concerns, Negative Self-Image, and Concerns with Public Attitudes about people with HIV/AIDS. According to these forms of measurement, which are based on standard representations of the experience of stigma, almost all HIV-positive people experience the effects of stigma.

Much has been written about the rhetoric of the gay community’s activism against AIDS with regard to confronting the stigma surrounding the disease. In response to the objectification of people with AIDS as sinners, victims, perverts, or criminals, gay activism used “identity-forming strategies” (Gamson 1989) to recreate a positive gay identity. Gamson and others (Gilder 1989; Dow 1994; Christiansen and Hanson 1996) refer specifically to kiss-ins, gay theater, and other forms of public protest focused on altering the gay community’s perception of itself in order to activate it
to address AIDS in a political way. Jennifer McGee asserts that “rhetoric produced in response to AIDS tends to focus on finding ways to re-constitute people with AIDS as actors rather than reactors, as human agents in control of their own fate rather than passive victims or sinners helpless in the grip of a shameful disease” (McGee 2003). This should be the goal of women’s AIDS activism as well, although the stigma on HIV-positive women is slightly different that that placed on gay men.

“In the United States many women infected with the human immunodeficiency virus (HIV) are poor women of African American or Hispanic American descent. Women with HIV have experienced many forms of oppression and discrimination and have been blamed as the victims of HIV and labeled as drug users, prostitutes, and carriers of acquired immune deficiency syndrome (AIDS). They have been stigmatized for their gender, their sexuality, their minority status, and their poverty, as well as for their HIV-positive status” (Bunting 1996).

Stigmas operate by psychologically separating a stigmatized person from the stigmatizer. In other words, by stigmatizing and placing blame and cause for discrimination on another individual for their situation, we are able to tell ourselves that such a thing would never happen to us. In the quotation above, Bunting sums up the stereotypes and stigma that haunt HIV-positive women specifically.

Many diseases prompt stigmas to form, but because of the mode of transmission and the communities most widely affected by HIV, HIV/AIDS patients experience significantly greater feelings of stigma than their peers who suffer from other diseases like cancer (Fife 2000). Even in the hospital, AIDS patients have been treated poorly: a former nurse who contracted HIV, Carole Chenitz, commented on the care she received as a patient, saying that “No one in the hospital staff took my hand, rubbed my back, gave me support, or did any of the comfort and care measures that we nurses pride ourselves on . . . I was unclean, untouchable, undesirable, a patient with a disgusting disease. If you get too close, you may get it, too” (Chenitz 1992).
Stigma has been associated with high-risk sexual behaviors (Preston et al. 2004), limited use of HIV services by infected individuals (Schuster et al., 2005), and delays in testing for persons in high-risk categories (Chesney and Smith, 1999).

Stigma also affects how willing individuals are to disclose their status and to engage in political activities and for this reason is a part of the HIV Stigma Scale mentioned previously. Looking at disclosure statistics for women can be helpful in understand how stigma effects a woman’s willingness to be public about her status. A study of Mostly African American women living in the South with an annual income of less than $10,000 found that most women (78%) reported disclosing their status within one week after diagnosis to at least one parent, followed by their husbands, siblings, friends, and children, or other intimate relations (Sowell 2003)\textsuperscript{16}. Sowell, et al. also found that women fall into different categories with regard to their decisions about disclosing their status: 49% practice full disclosure, 38.5% have criteria for disclosure based on their prediction of the reaction of the other individual, and 12.5% practice emotional disclosure based on their personal relationship with an individual and that person’s ability to keep the information confidential (Sowell 2003). On the other hand, in looking at whether women disclose their HIV status to their own children, some researchers found disclosure rates to be as low as 30% (Armistead et al., 2001). In other words, less than half of all women interviewed said that they were willing to tell anyone about their HIV status\textsuperscript{17}. Many forms of political activism require that individuals practice full disclosure or, at the very least, forego their privacy in order to participate in organizations and speak before groups, etc.

\textsuperscript{16} It is stated in the report of the study that they believe this to be the only study that has been done about general disclosure practices and preferences of women in the US. Whether or not there have been other studies at all, there is a clear dearth of research on the topic. That being the case, these statistics could vary based on the influence of other factors not documented in this study.

\textsuperscript{17} One issue which may account for the variance in statistics is that the women who are less likely to disclose are also less likely to be willing to be interviewed for such a study or even be aware of such a study.
C. Family Considerations

The issues that women face with regard to stigma can be considered to be similar to those faced by homosexual males or other groups that are affected by HIV; however, many HIV-positive women are also mothers and primary caregivers, and must therefore consider their families before they become politically active on HIV issues. The HIV Cost and Services Utilization Study (HCSUS) found that 76% of women receiving care for HIV had children under the age of 18 in their homes (Schuster 2000). Most women who contract HIV are in their reproductive years, and often are the primary caregivers for their children (CDC, 1999; Murphy, Marelich, & Hoffman, 2002). Many are mothers of multiple children, some of whom may not be infected with HIV (DeMatteo et al., 2002).

In a book on gender and political participation, Nancy Burns (2001) suggests that having children could cause mothers to have a greater sense of political responsibility, or alternatively, could absorb so much time and attention that mothers would have few opportunities to become involved. In the particular case of AIDS activism, it should also be considered that many mothers are concerned with how public knowledge of their own status will affect the way that community members respond to their children.

Burns also reports that while marriage does not increase average political activity, having a marriage end due to divorce, separation, or death of spouse significantly decreases the likelihood that an individual will engaged in political activism. Anne Phillips (1991) wrote that, for women, marriage often decreases possibilities for democratic participation due to the tendency for husbands to make political decisions for the entire family and to the work load that contemporary women undertake in working inside and outside the home. It is likely that even when couples do participate in AIDS activism together, they do not focus on the issues that affect women most.
E. Financial Concerns

The financial concerns of women with HIV are not only great, but are often greater than those of other groups who are also infected with HIV, as the literature used in the Community Profile of this paper showed. While the economic struggles that women face are often intimately tied up in their family situation, this must also be pulled out as a separate issue because not all women living in poverty with HIV are mothers. Organizations must look for ways to respond and be sensitive to the economic needs of their clients and activists.

F. Lack of Education or General Skills

For civil participation to democratically occur, it is essential to overcome the embedded inequalities in status, technological knowledge, and power that persistently undermine “linguistic and epistemic authority” (Chandoke 2003). As Chandoke would agree, complex democratic systems harbor forms of inequity and discrimination with regard to who is able to participate. In other words, the formal government system often does a poor job of valuing different sources of and forms of knowledge.

Communication skills and presentation are important elements for success in the political process. On an even more basic level, literacy is rather essential as well, for two distinct reasons. First, such skills are often a practical necessity. But on a different note, people with low literacy may feel less confident speaking with authority to government officials (Weir 2001). Approximately 21% of American adults are functionally illiterate, and another 27% have marginal literacy skills (Davis 1998).
G. Unfamiliarity with Political Process

Many people who are fully literate and confident in a public setting may struggle with a different type of lack of education, that is, lack of civic education knowledge about how policies are formed in the United States and how one would go about influencing those policies. The correlation between level of civic education and political participation is strong (Galston 2004). For this reason, a part of advocacy training must be civic education.

The information included in civic education need not be specific to HIV issues. Labor unions are often very good at promoting civic education as a path for encouraging involvement in making policy demands. The National Electrical Manufacturers Association has one such Government 101 course online that contains information that would be applicable to this case in many ways.¹⁸

¹⁸ The National Electrical Manufacturers Association’s Government 101 course can be found at http://www.bipac.net/page.asp?content=government_info&g=nema&parent=BIPAC.
Research questions

This paper will analyze the following research questions:

1. To what extent are HIV-positive women engaging in activism to influence the decision-making process that forms policies about HIV?

2. What are the barriers to activism and what are the ways in which organizations can foster the political involvement of HIV-positive women?

In order to address these questions, I will look at how the interviewees define ‘political involvement’, and whether they participate in direct advocacy activities, like voting, lobbying, and acting as a representative or spokesperson before decision-making bodies, as well as whether they participate in indirect advocacy, movement-building activities, like conducting peer education and forming networks and alliances with other HIV-positive women. I am also interested in determining the main barriers that women and the organizations that support them face in becoming politically active. The literature suggests that the main challenges to advocacy include health, stigma and reluctance to disclose status, family considerations, financial concerns, lack of education or general skills, unfamiliarity with political process. I will be elaborating on these challenges and looking for other challenges that affect one’s ability to take part in advocacy.

In responding to these challenges, what are the supports, tools, and methods that organizations can utilize in order to foster activism and keep women involved in advocacy in the long-term? What kinds of activities and trainings might be included in a curriculum that would give women the necessary tools to advocate for themselves and other women like them?

The literature about social movements and about women with HIV provided here provides some insights into these questions, but there is a lack of literature that directly approaches the issue
of HIV-positive women engaging in activism. This paper will be an exploratory project, taking a
grounded approach to explore some of the concepts explained in the literature, and adding some
ideas, recommendations, and insights to what has already been researched.
Methodology

The women interviewed for the purposes of this study were participants in the October 2007 Microbicides and Advocacy Training Conference held in Washington, DC by The Women’s Collective. The Microbicides and Advocacy Training Conference gathered 24 women from across the U.S. to learn more about microbicides and how to advocate for more funding and research to support the development of microbicides. Each conference participant was nominated to participate by an organization that she is involved with in her home city. I interviewed 19 of the conference participants, after receiving informed consent according to the IRB standards (See IRB application and approval in Section VI of this portfolio).

The conference was focused on action to support increased funding and research about vaginal microbicides, which are gels or creams that could be applied by women or men to the genital region in order to kill the HIV virus. TWC and other organizations recognize microbicides as an important step that would put prevention in the hands of women. Additionally, TWC has made an important contribution to this message by pointing out that microbicides would provide additional reproductive and sexual options for HIV-positive women and men. Microbicides are still in the research and development phase, but it has been estimated that with the institutional and financial commitment of the NIH, an effective microbicide could be on the market in five to seven years. Even if this product were only 60% effective, it could avert 2.5 million cases of HIV over a three year period19. During the period during which this project was being conducted (August – April) there were several advances made in U.S. legislation and medical research about microbicides. In February, the first Phase III trial on a microbicide closed, declaring Carraguard to be safe, but not effective. Several other microbicides are in Phase II testing. In April, the U.S. Congress voted to

19 More information about microbicides can be found at the website for the Global Campaign for Microbicides: http://www.global-campaign.org/about_microbicides.htm
include a piece about microbicides in the President’s Emergency Plan for AIDS Relief II (PEPFAR II).

The conference was centered on advocacy for microbicides, but also included general advocacy training, like a Capitol Hill tour, strategy sessions, and media training, which would be beneficial to advocates working on any issue.

Both the mean and the median ages of participants were 45, and the range was 31 to 74. The racial composition of the conference participants is similar to the epidemiological information for HIV/AIDS in the entire U.S. (See Figure 7).

![Figure 7. Race of TWC Conference Participants](image)

Also, 8 of the 19 women represent the South, which is a major area of concern for HIV infection. The locations represented by the conference participants can be seen on Figure 8, where each dot corresponds to a participant.
The conference participants were, for the most part, already very active in advocacy against AIDS. Three of them have founded their own HIV organizations; many of them serve on Ryan White Planning Councils; and most of them have spoken before large groups of people on behalf of women with HIV. Despite the fact that they are a non-representative portion of the HIV-positive, female population (based on the idea that most HIV-positive women do not engage in activism to such a degree), I have spoken with them based on their ability to represent many communities in diverse geographic regions. Based on their geographic diversity, they have had contact with different communities of women and have knowledge of a wide variety of issues that affect women.

I conducted two semi-structured interviews (see Appendix A) with these women in order to ask them questions about their past experiences with barriers to advocacy and working to overcome them. Specifically, interviewees were first asked to define political involvement. They were then asked to speak about the kinds of activities they have taken part in related to HIV – volunteering, conferences, and so on. They were then asked about the barriers that they personally had faced in being politically active. I also asked these women to speak about the experiences of other women in their communities, as well as about how organizations like The Women’s Collective can support women in becoming involved in influencing policy. The second interview was a follow-up, asking about their involvement and challenges since the conference.
Women’s involvement in HIV-related activities was judged based on eight categories of involvement, including: 1) being a client at an ASO, 2) being a volunteer at an ASO, 3) being an employee (usually a peer educator or case manager) at an ASO, 4) being a speaker at schools, prisons, and churches, 5) sitting on a planning council, 6) community organizing, 7) attending or putting together conferences, and 8) lobbying members of Congress or other elected officials (See Appendix B).

Based on the literature review, it was expected that interviewees would describe six different types of barriers of challenges to advocacy, including: 1) health, 2) stigma and reluctance to disclose status, 3) family considerations, 4) financial concerns, 5) lack of education or general skills, and 6) unfamiliarity with the political process. For this most part, these categories are fairly straightforward and presented themselves clearly in interviews. Family considerations were represented either as an unwillingness to disclose due to considerations of one’s children, or as a lack of alternative child care. Financial concerns were represented as problems with either housing, food, or transportation. Challenges were noted even if interviewees did not directly mention them in responding to this question, but also, for example, if an interviewee mentioned having been involved in housing advisory councils because she was homeless.

For questions about the voting habits of or involvement of other women in interviewees’ communities, they were asked to respond to questions by saying that “Very Few”, “Some”, or “Many” women participate in these activities.

While 19 women participated in the first interview, 11 participated in the second interview (a participation rate of 58%). The first of these interviews took place in October during the conference, where I took some time to speak to each participant individually. One woman, who was interviewed before the conference, was ultimately unable to attend because of an issue with her housing situation. The busy schedule of the conference did not allow for interviews with all of the
women to take place, and the women who were not interviewed were women who were not easily contacted or very busy after the conference. The second interview was held by phone in February and March. Of the 8 women who participated in the first, but not the second interview, 5 of them were in poor health and 3 of them were busy or not easily contacted. I also created a survey-style conference evaluation that the women completed at the end of the conference to provide TWC with some feedback about the conference specifically.

Additionally, I spent approximately 9 hours per week in The Women’s Collective office. During this time, I was not following any particular observational protocol; however my experiences there and what I was able to see in the office influenced my perspectives on this topic and added greatly to my understanding of the issues involved. My time at TWC was spent helping with the Policy and Advocacy Department’s work on planning and attending events, contacting the conference participants, summarizing legislation and writing articles for the bimonthly newsletters.
Results

In analyzing the results of these interviews, I was interested in which responses were the most common. I was also interested in answers that were not addressed in my literature and the other information that I have been exposed to on the topic.

To what extent are HIV-positive women engaging in activism to influence the decision making process that forms policies about HIV?

Among a group of women targeted to participate in advocacy:
How do they define political involvement?

When asked how they defined political involvement, many women gave answers that focused on lobbying in Congress, influencing bills, or speaking to elected officials at high level. Only five women gave answers that focused on more generalized expressions of political involvement such as “having a voice” or “community education.”

Figure 9. Political Involvement, defined by interviewees
Are they voters? Do these women choose their political representatives based on HIV-related issues? What are their perceptions of the voting habits of other WWA?

The majority of the women interviewed do vote (Figure 10); and of the three that do not vote, two of them are not citizens of the United States and therefore to not have the option to vote. The majority of voters reported that they sometimes considered HIV-related issues when making voting decisions, but there was a wide range of answers in that several interviewees gave answers on opposite ends of a spectrum, replying that they either rarely or usually thought about HIV-related issues in making political decisions. Several of them made references to organizations that distribute information about the HIV/AIDS policies of political candidates.

**Figure 10. Voting Habits of Interviewees**

Of the interviewees who said that they sometimes or rarely considered HIV/AIDS policies when voting, many of them mentioned other issues that influence their political decisions (Figure 11). The most commonly referenced issue was a more general concern for women’s and reproductive health issues, followed by family or children’s issues. Other issues mentioned ranged from medical marijuana to general health care issues, often based on the concerns the area of residence of the interviewee.
Most interviewees reported that their perceptions of other women with HIV/AIDS is that very few of them vote, and that they probably do not think about HIV-related issues when making political decisions (Figure 12).

Figure 11. Consideration of HIV Policies in Voting, by voting interviewees

Figure 12. Population of HIV-Positive Women that Vote, according to interviewees
Do they participate in lobbying? Do they work to build networks and coalitions and organize campaigns to educate their communities and influence policy? How are they able to represent themselves on committees and decision-making bodies? What are their perceptions of the involvement of other WWA?

A vast majority of the interviewees are volunteers with some ASO and have spoken publicly about their experiences with HIV/AIDS (Figure 13). Fewer, but still more than half of the interviewees are employed by an ASO, participate in community organizing, attend HIV-related conferences, represent WWA on planning councils or committees, and participate in lobbying.

**Figure 13. Involvement of Interviewees in Political or Advocacy Activities**

Most of the women who were interviewed in the second round said that, since the conference, they had been more involved in advocacy than they had previously been. They had been involved in a variety of activities (Figure 14), and worked to incorporate what they had learned at the conference about microbicides into their other work.
Most interviewees reported that they perceived the majority of HIV-positive women to not be involved in any sort of political activity.

**What are the main barriers that organizations and individuals face in mobilizing groups of women to be political active?**

*What challenges to political activism do HIV-positive women face?*

By far, the most common challenge mentioned by interviewees was the stigma surrounding HIV/AIDS, which often causes people to be fearful of disclosing their status (Figure 15). Another challenge that this group of women reported experiencing is that political involvement can be emotionally draining. Many of the women interviewed had been involved in advocacy for many years, and said that when progress was slow, it was often difficult to maintain dedication and a positive attitude.
Interviewees were also asked to speak about the challenges that they witnessed other women facing, or the reasons why HIV-positive women in their communities might not be politically involved (Figure 16). By far the most common challenge that interviewees talked about was, again, the problem of the stigma surrounding HIV. Most interviewees talked about the stigma in a more general way and referred to the fear of stigmatization as a major barrier to advocacy because it prevents individuals from being willing to reveal their status as HIV-positive. Interviewees were not asked directly to share their experiences with direct stigmatization, but several did so anyway. One participant said that after she contracted HIV through heterosexual contact with a man that was using drugs intravenously, another woman in her community wrote a vindictive article in the newspaper, claiming that, “She deserves this.” Other participants said that they felt “tokenized” in their role of advocates or political activists, or held up as unrealistically one-dimensional representatives of all HIV-positive women. Because so many HIV-positive women are not vocal about their status or experiences, the few that are very active are tokenized in their role as representatives. Several of the interviewees from the South said that they believed that the problem
of stigmatization is especially apparent in the South and in rural areas, where there is very little education about HIV.

**Figure 16. Barriers Faced by Other HIV-Positive Women, as reported by participants**

While few women mentioned a lack of knowledge about the political process as a challenge, many of them later said that training workshops explaining the political process were among the major needs of women that can be filled by organizations trying to increase their involvement. They said that these workshops should include information on how to speak with and get the attention of relevant public officials.

One of the issues that came up in several interviews was the low level of education among many HIV-positive women. Not only does lack of education cause far-reaching problems in the lives of women in terms of the ability function in everyday life and find gainful employment, but it also causes many to be self-conscious about their educational level when speaking with elected officials or policy makers, or just speaking in public in general.
While few of the participants mentioned lack of food, transportation, housing, or child care as challenges that they personally faced, about half of them mentioned at least one of these material challenges as something faced by many participants in their communities. Financial problems displayed themselves in more indirect ways. For example, one participant explained that although she wanted to work she had not been able to because if she were earning a salary she would lose her public benefits. This is problematic because she could not earn as much by working as she was receiving from public benefits, and because if she lost the benefits and then got too sick to work, it would take a long time to go through the paperwork to get benefits again. She was excited however because she had just gotten part-time employment at an ASO, where her salary would be under the threshold so that she could keep her public benefits.

In conducting the second set of interviews, many participants either could not participate or had not been involved in advocacy as a result of health problems. While this was not an issue that participants listed as a challenge in the first interview, many participants were or had been very sick. One participant had been forced to cancel a workshop because of illness. Another participant had had a miscarriage and another woman’s eyesight had gotten so bad that she could not drive, and could not speak on her cell phone for a long period of time from home because of financial concerns.

What are the challenges facing organizations that aim to encourage activism among HIV-positive women?

The most obvious challenge faced by organizations in trying to foster activism is trying to help clients overcome their own personal challenges. This is particularly problematic because the challenges and needs faced by clients are often very diverse and not a “one-size-fits-all” situation, as one interviewee said. But also, when asked about the challenges that they personally have faced in their efforts to be activists, several of them spoke about challenges faced at an organizational level in their jobs or volunteer positions. These challenges were often related to financial resources. One
interviewee explained, at length, how difficult it is for people in her neighborhood to get grants in order to conduct programs and carrying out projects. She said that once women had their grant applications rejected once, they were unlikely to apply again. Another interviewee explained that the organization she works with has been unable to gain recognition as a 501(c)3 non-profit organization, which has made it more difficult for them to operate and raise funds.

Most challenges mentioned in the interviews were consistent with the current research literature on this topic. However, one issue that was not previously expected came up in two interviews. These two interviewees explained that they are very involved in their church communities and that their social networks are largely based on these religious communities. Because of this situation, it is a challenge for them to share the information that HIV/AIDS organizations and public health officials provide. Peer education programs and other workshops that involve the distribution of condoms and the discussion of sexual acts are not always welcomed in a church environment.

**How can community-based organizations organize and empower women to play an important role in policy making decisions?**

What kinds of supports and methods are most effective in fostering activism? How can CBOs keep women involved even when the process is discouraging?

The most commonly mentioned need was education – both basic education and education on how to be an advocate. Participants explained that other women they encountered often did not know how to go about changing policy and how to talk about different issues. Others spoke about education as a mechanism for allowing people to “see outside of their box” and awaken a political consciousness. Participants also expressed the need for advocates to be trained in how to speak to certain communities of people – specifically religious communities – about issues related to HIV.

Other participants focused more on the need for empowerment. While some participants mentioned empowerment specifically, others referred the need for microenterprise programs that
Other participants suggested that would-be advocates need to hear success stories from others, and should also earn rewards or completion certificates if they complete an advocacy training course. Also as a form of empowerment, one participant talked about the need for advocates to be encouraged to move beyond the role of participants and become an organizer within an ASO.

In the second interview, interviewees overwhelmingly said that their personal contacts with TWC had been very helpful. One interviewee said that she had been inspired attempted to change the environment of the organization she worked with at home in order to make it more personal. Others said that it was helpful to always know that they were supported in a personal and professional way by the staff and could call at anytime.

Other participants talked about who was responsible for encouraging advocacy. One participant was adamant that case managers in ASOs must be the link to getting women involved in advocacy. Another said that disclosure must become a focus of the work of ASOs.

The second set of interviews focused on several of the things that TWC has done to keep advocates involved and informed. These include holding conference calls about every three weeks, sending out bimonthly newsletters (see appendix), creating CDs with powerpoints and handouts about microbicides for use in outreach, and maintaining personal contact. Participants said that all of these mechanisms had been effective in supporting them and keeping them informed and in contact. However, many participants said that timing was a problem for the conference calls, and some said that they did not know how to use powerpoint and therefore had not used the materials included in the CDs.

What would be included in a curriculum that would give women the tools to advocate for themselves?

What should be the most important goals of the curriculum? What kinds of activities and trainings would be most effective?
The most commonly discussed need of would-be advocates is the need for basic training in how to go about becoming politically involved and how to influence policies. In connection with this idea, several interviewees mentioned the need for organizations to provide many options for how to become involved, to allow for people to slowly expand their comfort zones based. For example, women might feel more comfortable calling the office of a member of congress or writing a letter than they would speaking at a rally or a conference. This need is related to the fear of stigmatization: women who are not yet ready to reveal their HIV-positive status would gravitate towards different kinds of advocacy activities than openly positive women. Also some women are hesitant to reveal their status in consideration of their children.

With regard to the role of the family in advocacy, although it can be a challenge, some interviewees mentioned that they were involved in advocacy because of their children. One interviewee said that she had gotten involved with advocacy in order to set an example for her child or how to take an active role in society and to prove that being HIV-positive was not something to be ashamed of. Other interviewees said that they were taking specific measures to get their own children involved. Several had taken their children to speak to government representatives or had gotten their children involved in organizations that encouraged advocacy. There are many children in the U.S. who were born with HIV in the mid- or late-1980s, which mother-to-child transmission rates were still very high. They are now about 20 years old, and there is a great need to reach out to this younger generation and encourage them to speak out about their situations.

Almost half of the interviewees said that it is important for women to have contact with other, more experienced HIV-positive women, and to hear success stories from their experiences. In many cases, these sorts of relationships and stories can work against the emotional strain of long-term involvement. At the same time, one woman expressed the concern that success stories can sometimes be overwhelming to people who have very little experience in being politically active.
Other women made suggestions including (among others) : empowerment initiatives, formulation of church appropriate messages, help with general education (reading, writing, and speaking skills), basic courses on HIV/AIDS with an element that allows women to practice speaking about HIV to other people, and incentives like a certificate of complete of a course.

Discussion

The interviewee’s reported stark differences in the barriers they faced versus the ones that other HIV-positive women face. While the majority of interviewees reported that their own primary challenge had been the stigma surrounding HIV, they reported that many other HIV positive women faced a set of other challenges. Stigma was just one of a long list of challenges that interviewees think others face, the most commonly mentioned of which being unfamiliarity with the policy-making process or with the issues involved. Since interviewees experienced stigmatization and very few other barriers, it could be that the stigma around HIV can be more easily overcome when other challenges are absent. These results suggest then that it is most important to address the issue of unfamiliarity with the political process. Stigma is a complex obstacle to overcome and interviewees report that even though they are active, they are still in the process of dealing with it. The steps to address unfamiliarity with the political process are more concrete and clear.

Another discrepancy in the information provided by interviews was that very few first-round interviewees reported that physical health had been a challenge to their advocacy in the past, but 5 of the 8 women who were unable to participate in the second interview were unable to do so because of health problems. Also, in answering the question, “What challenges have you faced in trying to be politically active recently?” in the second interview, none of them responded that health had been a challenge, but three of them mentioned in other parts of the interview that they had been in poor
health. Either interviewees did not view health in terms of being a barrier for advocacy, or they were reluctant to admit that they had health problems. Both statements are likely to be true with different women. Since only five interviewees reported that poor health was a barrier for other women, it is likely that many interviewees were not considering health in terms of being a barrier. Since some of the interviewees have been HIV-positive for so long, they are very proud of continuing to maintain their health and would be reluctant to admit illness.

Analysis of this data was generally very straightforward in terms of coding interviews because the categories of barriers and terminology used to speak about the challenges that accompany HIV were very well-known and understood by those women interviewed. It was clear that the interview participants had thought about this issue previously and had probably read or talked about it as well.

Additional Findings

One unforeseen issue that several women mentioned is that their lack of citizenship status made it impossible to vote. This could potentially inhibit their ability to participate in other activities or even to receive public benefits. Another issue which did not originally appear in the literature is that some HIV-positive women already have negative standing in their relationship to the state as a result of being convicted of crimes. These are issues in and of themselves; however, without even attempting to directly address these issues – there are roles that such women can play in advocacy.

Another barrier that was not specifically addressed in related literature is that of burn-out or the fact that advocacy is an emotionally draining endeavor. It is not surprising that this issue was mentioned, especially because many of the interviewees are long-term survivors and advocates. Although they were not directly asked, many interviewees revealed that they had been HIV-positive
for 15 or more years. In recognition of this challenge, advocacy programs must endeavor to support long-term advocates in addressing their own unique challenges.

One potential group of advocates that should be explored and supported is the HIV-positive youth, and specifically the teenagers that were born with HIV in the 1980s before mother-to-child transmission was stopped in the U.S. These young people have a vested interest in developing better policies for the future and have creative and different ideas. This group of youth that was born with HIV is just now coming of age and it is important that they begin to see the political aspects of the disease that they are living with.

Citizenship, exclusion from the political system as a result of criminal records, and youth HIV-positive advocacy are not topics that have been explored in literature available on many online research databases.

**Methodological Limitations**

It must be emphasized that almost all of the women interviewed for this paper were invited to the conference because they were already involved in advocacy. As their interview results show, they had founded organizations, spoken at conferences, and been representatives on planning councils; but they reported that very few other women were involved in advocacy. To gain a more comprehensive perspective on the barriers faced by women and the needs of women in terms of becoming advocates, it would be necessary to speak with HIV-positive women who had not been involved in advocacy.

Furthermore, while individual interviews were an important method for connecting with individuals about their experiences and thoughts, other methods of investigation would likely produce different results. For example, if interviewees were given a list of possible barriers and asked to check off the ones that they had experienced, the results may have been different. Also,
having all of the interviewees participating in a focus groups to discuss these issues may generate a different set of conclusions. Ideally, all of these methods would be used in conjunction over a longer period of time.

Another possible limitation of this particular study has to do with the fact that I was associated with an advocacy department that is almost exclusively working on advocacy around microbicides. Although I framed my interview questions by saying that I was asking “about advocacy in general, not just about microbicides,” many interviewees responded in reference to microbicides specifically. For example, when I asked interviewees in the second interview what challenges to advocacy they had faced since the conference, and added that I was asking “about advocacy in general, not just about microbicides,” maybe interviewees still responded by saying that advocacy around microbicides is challenging because it is a complex topic and because, since no microbicides are on the market right now, it is not a concrete topic to discuss.

**Suggestions and Best Practices**

The following is a list of the basic recommendations that emerged from interviews for programs that are meant to support and encourage the political involvement of HIV-positive women. In order to be successful, such programs should:
• Prioritize the need to address unfamiliarity with the political process on the part of HIV-positive women.

• Be family-centered, addressing family issues and involving the voices of all family members.

• Be incorporated into and encouraged by other programs within an ASO; Case managers, prevention outreach teams, support groups, etc. should all play a role in encouraging advocacy.

• Allow HIV-positive women to set the agenda and serve in leadership or organizing roles.

• Provide women with many options for how to get involved, based on the specific concerns and needs of different women.

• Make efforts to maintain personal contact with advocates.

• Formulate messages and programs with regard to participants’ cultural context, especially their involvement in religious communities.

• Make efforts to incorporate those people that have been excluded from the political system based on their criminal records or citizenship status.

Conclusion

This research should serve to better explain the challenges that face HIV-positive women and all-too-often prevent them from participating in political advocacy about the issues that shape their everyday lives. This research can be used by organizations that are conducting informal
advocacy activities or by service-based AIDS organizations that do not focus on advocacy, in order to help them more effectively direct their efforts.

The women that participated in this study were asked to speak to both their own experiences and the experiences of other women in their communities. Based on the criteria for attending the TWC Conference and being asked to participate in this research, the participants in this study were already a great deal more involved in advocacy than many of their peers. One of the most important steps that could be taken to deepen the understanding about what barriers face HIV-positive women would be to conduct interviews or focus groups with women who are not particularly involved with advocacy.
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APPENDIX A

This section includes the protocols for the two interviews, as well as the survey distributed after the conference.

The Women’s Collective
Political Activism

Interview Protocol
First Interview

Date_____________    Time_____________   Location_____________
Number_____________

Thank you for taking time to talk with me today.

1. I’d like to start by asking you about the types of HIV/AIDS organizations with which you work.
   a. What organizations are you involved with?
   b. What are the main activities of these organizations?
   c. What is your role within this/these organization(s)?
      ⇒ Do you receive services from any organizations that are especially for HIV-positive people? Do you attend meetings or volunteer with any organizations?

2. Next I’d like to ask you about your political involvement?
   a. First, how would you define “political involvement”?
   b. Are you a regular voter?
   c. When you are voting for legislation and candidates for political office, how often do you consider how these candidates or this legislation will impact issues related to HIV/AIDS?
   d. Beyond voting, have you engaged in any forms of political activism?
      For example:
      i. serving on local committees or decision making bodies
      ii. engaging in community organizing
      iii. building networks to educate the community?
   e. What challenges or barriers have you faced to engaging in political activism related to HIV/AIDS?
3. Now I’d like to ask you about your perceptions of how socially and politically engaged are other HIV positive women with whom you interact personally or through the organizations with which you work?
   a. Thinking about other HIV positive women that you know, do you perceive that they are regular voters?
   b. Do you think these women often vote based on how they think candidates or legislation will impact issues related to HIV/AIDS? Please explain.
   c. How many of these women (percentage, estimate of proportion) do you think engage in political activities including:
      i. serving on local committees or decision making bodies
      ii. engaging in community organizing
      iii. Building networks to educate the community?
   d. What challenges or barriers do you think these women have faced to engaging in political activism related to HIV/AIDS?

4. Finally, I’d like to ask you some questions about how to support political activities among HIV positive women?
   a. First, do HIV/Positive women in your community think that their political voice is important?
      i. Do you and other women engage in dialogue about being politically active
      ii. Do you and other women think that your political voice is important?
   b. What do you and other women need to support political action related to HIV/AIDS
   c. Specifically, we are considering developing a curriculum for political activism related to HIV/AIDS.
      i. What do you think would be most helpful to be included in this curriculum?
      ii. Are there activities that you think would be most beneficial?

5. I would also like you about the following form about demographic data. It’s completely optional.

   Race:

   Age:

   Previous Knowledge about Microbicides:

6. I don’t have any additional questions for you. Do you have thoughts you’d like to share that were not directly asked?

Thank you for taking time to talk with me this (morning/afternoon/evening). I will follow up with you for our next interview in (give time).
# Microbicides Conference Evaluation

**October 11\(^{th}\) - 14\(^{th}\)**

On a scale of 1-10, please rate the following statements: (10=Absolutely! and 1=Not at all)
Feel free to comment on or explain any of your responses.

1. This conference met my expectations.
   
   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | N/A |
---|---|---|---|---|---|---|---|---|---|----|-----|

2. During this conference, I met many incredible women who I want to stay in touch with.

   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | N/A |
---|---|---|---|---|---|---|---|---|---|----|-----|

3. When I return home, I plan to be more politically involved than I was before.

   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | N/A |
---|---|---|---|---|---|---|---|---|---|----|-----|

4. Because of this conference, I feel more confident that my political voice is important.

   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | N/A |
---|---|---|---|---|---|---|---|---|---|----|-----|

5. I learned a lot about microbicides and why they are important for me and my friends.

   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | N/A |
---|---|---|---|---|---|---|---|---|---|----|-----|

6. I now have enough knowledge to be able to share what I learned with my community at home.

   | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | N/A |
---|---|---|---|---|---|---|---|---|---|----|-----|
Please rate the following parts of this conference to tell us if it was HELPFUL (5) or NOT HELPFUL (1) for you.

<table>
<thead>
<tr>
<th>Day 1</th>
<th>not helpful</th>
<th>helpful</th>
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<tbody>
<tr>
<td>Microbicides 101</td>
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<tr>
<td>Making Mimi Microbicide</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Peer Advocacy</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Intro to Microbicides Development Act</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Lobbying Part I: Lobbying Congress</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Capitol Hill Tour</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Capitol Hill Representative Visits</td>
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<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Day 2</th>
<th>not helpful</th>
<th>helpful</th>
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</thead>
<tbody>
<tr>
<td>Capitol Hill Debriefing</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Lobbying Part II: Next Steps</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Media Training</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Strategy Session</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Check the boxes below for each thing that you think you accomplished during this conference.

- [ ] Networking
- [ ] Lobbying
- [ ] Knowledge of microbicides
- [ ] Learning to talk to the media

What was the most helpful thing that you learned at this conference?

What is your favorite memory of this conference?

How do you expect to be involved with The Women’s Collective in the future?
The Women’s Collective  
Political Activism  

Interview Protocol  
February 2008  

Date_____________    Time_____________   Location_____________  
Number_____________

Thank you for taking time to talk with me today.

1. I’d like to start by asking whether your advocacy activities have changed since the TWC conference.  
   a. Are you any more of less involved in advocacy than you were when we first spoke?  
   b. Have you incorporated information from TWC about microbicides into your other advocacy activities?

2. Now I would like to ask you about your interactions with TWC.  
   a. Overall, has TWC been helpful to you?  
      For the following questions, please answer with one of the following three options: Very Helpful, Somewhat Helpful, or Not Helpful  
   b. Have the conference calls been helpful?  
   c. What about the newsletters?  
   d. Have the other materials (powerpoints, flyers, letter templates) been helpful?  
   e. And finally, has your personal interaction with TWC staff (through phone calls, etc.) been helpful?

3. Now, what about the connections with other women who you met at the conference – have those relationships been meaningful?

4. What challenges have you faced in trying to be politically active recently?

5. Finally, what are your advocacy plans for 2008?

6. I don’t have any other questions for you. Do you have thoughts you’d like to share that I did not directly ask about?

Thank you for taking time to talk with me this (morning/afternoon/evening).
APPENDIX B

Interview 1: What does "political involvement" mean to you?

<table>
<thead>
<tr>
<th>Definition</th>
<th>Answer focused on Congress and lobbying?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having a voice for what you believe in</td>
<td>No</td>
</tr>
<tr>
<td>2. Advocacy on Capitol Hill to change policies</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Learning and teaching; talking to people about an issue</td>
<td>No</td>
</tr>
<tr>
<td>4. Protesting that there are 250 people on the ADAP waiting list;</td>
<td></td>
</tr>
<tr>
<td>5. Talking to representatives; Getting on TV</td>
<td>Yes/No</td>
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<tr>
<td>6. Community education</td>
<td>No</td>
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<tr>
<td>7. Changing public policy and getting to know politicians;</td>
<td></td>
</tr>
<tr>
<td>8. Learning and teaching; talking to people about an issue</td>
<td>Yes/No</td>
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<tr>
<td>9. Having a voice</td>
<td>No</td>
</tr>
<tr>
<td>10. Letting legislators know what's going on; getting groups together</td>
<td>Yes/No</td>
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<tr>
<td>11. Educating community and decision-makers; fighting for what you believe in; empowering others</td>
<td>Yes/No</td>
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<tr>
<td>12. Helping out in a political campaign</td>
<td>Yes</td>
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<td>13. Educating legislators</td>
<td>Yes</td>
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<td>14. Trust issues about politicians, hopelessness</td>
<td>Yes</td>
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<tr>
<td>15. Community education</td>
<td>No</td>
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<tr>
<td>16. Meeting with representatives (says she doesn't do it)</td>
<td>Yes</td>
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<tr>
<td>17. Talking to representatives</td>
<td>Yes</td>
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<td>18. Testifying before government officials</td>
<td>Yes</td>
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<td>19. Educating the community and politicians</td>
<td>Yes/No</td>
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<td>20. Changing bills in Congress</td>
<td>Yes</td>
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<tr>
<td>21. Lobbying Congress, city council, and neighborhood groups;</td>
<td>Yes/No</td>
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<tr>
<td>22. working to make DC a state</td>
<td>Yes/No</td>
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## Interview 1: Voting Habits

<table>
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<tr>
<th>Voting</th>
<th>Voting of other WWA</th>
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<tr>
<td>Do you vote?</td>
<td>Choose candidates based on HIV policy?</td>
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<td>1</td>
<td>Yes</td>
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### Interview 1: Forms of Involvement of Participants

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<tr>
<th></th>
<th>Client</th>
<th>Volunteer</th>
<th>Educator/Case Manager</th>
<th>Employee/Peer</th>
<th>Speaker</th>
<th>Planning Council</th>
<th>Organizing</th>
<th>Conferences</th>
<th>Lobbying</th>
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### Interview 1: Challenges Faced By Participants

**Challenges - Personal**

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* Note: In this case, financial concerns were displayed as problems related to the participant’s housing situation
Interview 1: Challenges Faced by other HIV-positive Women, as reported by participants

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* Note: Financial concerns included transportation, food, and housing

** Note: only 7 participants mentioned lack of knowledge about how to be an advocate with asked about barriers to advocacy; however, twice as many mentioned training about how to be an advocate as a need that could be fulfilled by ASOs
## Interview 1: Advocacy Needs of HIV-positive Women

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<th>Church-appropriate info.</th>
<th>Empowerment</th>
<th>Advocacy 101; who to talk to, etc.</th>
<th>Mentors, and success stories</th>
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- **What do women need to be better advocates?**
  - Certificate of completion of course
  - Crafting Circle: Microenterprise
  - See outside their box
  - Case managers should talk about advocacy
  - Education on how to talk about HIV, importance of disclosure
  - Info on voting
  - Need to move beyond being a participant to being an organizer
  - Bring young people to the table to share their ideas
### Interview 2: Involvement in Advocacy since TWC Conference

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### Interview 2: Forms Involvement since TWC Conference

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Interview 2: Efficacy of TWC Mechanism of Support

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Interview 2: Continued Contact between Conference Participants

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## Interview 2: New Challenges to Advocacy Faced by Participants

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<th>Microbicides is difficult; not knowing what to do next</th>
<th>Not accepted into program</th>
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