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April 16, 2012

“Women, Infants, Etc.”: Gender and Vulnerability in U.S. HIV Legislation and Policy

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Abstract

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The purpose of this thesis is twofold. My first goal is to unite the conversations of feminist theory on HIV disease, feminist legal theory, and feminist legal vulnerability theory in order to establish an interdisciplinary and intersectional framework of analysis that can be used to navigate the complicated scholarship about HIV disease. In addition, I note the progression of feminist legal theory on HIV disease as well as a new concept of feminist legal theory developed by Martha Fineman known as vulnerability theory. The second goal of this project is to use this framework to explore and critique the ways gender is deployed in the domestic laws about HIV. The specific laws I will explore are the Ryan White CARE Act of 1990, The Ryan White Treatment Extension Act of 2009, and the Patient Protection and Affordable Care Act of 2010. Each of these laws speaks to gender in a specific, traditional, normative way that has devastating consequences for both women and men with HIV. Through the use of the interdisciplinary and intersectional feminist framework built in this paper, these laws can be both analyzed and reformulated in order to better and more efficiently address the needs of women with HIV disease.

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Acknowledgements

*I learned many things from writing this thesis,
Like how to check out a study room in the library,
Where to get the best markers for the whiteboards,
And that the stacks stay open until 2AM on weeknights.
I learned what the word “antiretroviral” meant,
How to keep myself awake until 4AM,
And even what time my advisor puts her kids to bed at night.
I learned a great deal about HIV disease,
About treatments, prevention, costs, and programs.
But most importantly,
I learned that this ‘Women’s Studies thing’,
Which I just so happened to stumble across in 2010,
Was worth pursuing.*

Dr. Sparks, you are an inspiration. I couldn’t have done this without you. All the hard work that we have put into this thesis was totally worth it. I am honored to have the pleasure of working with you.

For women with the Human Immunodeficiency Virus.

Table of Contents

Acknowledgements

I. GENDER, HIV, AND FEMINISM 1

II. FEMINIST SCHOLARSHIP ON HIV/AIDS 5

 A. Feminist Theory: Gendering HIV

 B. Feminist Legal Theory and HIV: Fighting for Women’s Rights

 C. Vulnerability Theory: A New Feminist Legal Framework for HIV Law

 D. Conclusion

III. “INFANTS AND WOMEN, ETC”: THE INVISIBLE ‘OTHERS’ OF THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT 32

 A. Introduction to the Ryan White CARE Act

 B. “Infants and Women, Etc.”: Funding Support Services and Research for the ‘Others’

 C. Criminalizing Pregnant Bodies

 D. HIV and Drug Users: The Intersectional Implications of Invisibility

 E. “Acting Against AIDS” in the Ryan White Treatment Extension Act of 2009: Individual Responsibility and the Vulnerable Subject

 F. Conclusion

IV. THE PATIENT PROTECTION AND AFFORDABLE CARE ACT 51

 A. Introduction to the Affordable Care Act: Ignoring HIV

 B. The Affordable Care Act’s Gendered Construction of Vulnerability: Consequences for Women with HIV Disease

 C. Personal Responsibility Education: Helping ‘Vulnerable’ Women with HIV to Avoid Pregnancy

 D. Conclusion

V. A VISION FOR THE FUTURE OF HIV LEGISLATION 64

 A. A Summary of the Interdisciplinary Approach

 B. The Responsive State: Improving the Health of Women with HIV

 C. Feminist Objections to Fineman’s Argument

 D. Conclusion

Works Cited 73

Works Consulted 77

CHAPTER 1: GENDER, HIV, AND FEMINISM

“We’re celebrating the second anniversary of the new health-reform law, the Affordable Care Act,” says Cindy Pearson, co-founder of Raising Women’s Voices, a national feminist organization that works to ensure better healthcare for women. When discussing why American feminists are so excited about the Affordable Care Act, Pearson says, “For a start, the law has already started removing barriers to healthcare and improving services for millions of women and our families, helping us access the care we need to stay healthy” (Pearson 2012). Like Pearson and her organization, many American feminists heavily support the Patient Protection and Affordable Care Act, signed into law on March 23, 2010, by President Barack Obama. The bill is attractive to them because of the benefits it provides women, such as helping them have better access to insurance coverage, eliminating contraception co-pays, and improving the health of older women.

While many feminists have praised the new law for its progressive stance on extending insurance coverage, I argue that the ACA and other domestic health legislation, including the Ryan White CARE Act, disserves women with HIV disease. The Ryan White CARE Act of 1990 and the Ryan White Treatment Extension Act of 2009 also regulate the care of people with HIV. While these laws give billions of dollars towards HIV prevention and treatment, I argue that they deploy gender norms and sexual roles in a traditional, restricting way that does not equally represent women with the disease. By addressing a neoliberal, presumably male subject, the laws governing domestic HIV are not sufficient to address the disease among people who do not fit these criteria. The legislation does not provide funding for people whose lifestyle choices or preferences are outside of the acceptable,

heteronormative mainstream and thus works to further marginalize many women with HIV.

For the past three decades, social scientists, legal scholars, public health scholars, and healthcare workers have all been trying to make sense of the HIV epidemic. Within each of these distinct groups, a specific type of theoretical discourse about HIV is articulated. While feminists and sociologists are discussing the way in which knowledge is situated around HIV disease and the problematic use of risk categories, public health scholars are using risk, behavior, and other epidemiological categories to study both domestic and international HIV. And while legal scholars are debating issues of pregnant women's rights, mandatory testing, and the inefficiency of the U.S. healthcare system, scholars in the natural sciences are striving to find an HIV vaccine and create drugs that better control viral load. Although these disciplines cover a variety of topics within the academic study of HIV, they are not often used to inform each other. When put in conversation, feminist scholarship on HIV and feminist legal theory on HIV can be very useful for exploring the law's problematic, traditionally gendered approach to HIV. However, even in tandem, these conversations lack the theoretical resources for approaching HIV that addresses women more fairly. For this, I will argue, we must turn to feminist legal vulnerability theory.

The purpose of this thesis is twofold. My first goal is to unite the conversations of feminist theory on HIV disease, feminist legal theory, and feminist legal vulnerability theory in order to establish an interdisciplinary and intersectional framework of analysis that can be used to navigate the complicated scholarship about HIV disease. The second goal of this project is to use this framework to explore and critique the ways gender is deployed in the domestic laws about HIV. The specific laws I will explore are the Ryan

White CARE Act of 1990, The Ryan White Treatment Extension Act of 2009, and the Patient Protection and Affordable Care Act of 2010. Each of these laws speaks to gender in a specific, traditional, normative way that has devastating consequences for both women and men with HIV. Through the use of the interdisciplinary and intersectional feminist framework built in this paper, these laws can be both analyzed and reformulated in order to better and more efficiently address the needs of women with HIV disease.

Chapter 2 will build the feminist framework of analysis that I will use to explore the legislation concerning HIV disease. I will trace the development of feminist scholarship on HIV disease, including feminist reactions to the heterosexualization of AIDS, post-structuralist feminist theory on HIV, and the recent shift in focus to the global epidemic. In addition, I note the progression of feminist legal theory on HIV disease as well as a new concept of feminist legal theory developed by Martha Fineman known as vulnerability theory. I argue that the use of an interdisciplinary, intersectional feminist approach in critiquing HIV legislation will result in the greatest understanding of the way our current domestic legislation both addresses the HIV epidemic and impacts the lives of women with HIV disease. It is when these different conversations are used to inform each other that a better analysis of domestic HIV legislation that is reflective of the experiences of women with HIV can be achieved.

With Chapter 3, I begin the stride towards the second goal of my project, which is to use the interdisciplinary and intersectional framework of analysis set up in Chapter 2 to explore the use of gender in the current laws governing domestic HIV research and care. The chapter will specifically discuss how the Ryan White CARE Act of 1990 deploys gender in a way that disserves women with HIV disease. Generally termed "Ryan White," the bill

became law on August 18, 1990, and serves as the domestic plan for HIV/AIDS funding and community based care. Since it first passed, the bill has been reauthorized four times, in 1996, 2000, 2006, and 2009, and it has provided billions of dollars to assist persons with HIV and their families (Blendon et al. 2011). I will also address the shift in focus from the Ryan White CARE Act of 1990 to the Ryan White Treatment Extension Act of 2009, the most recent renewal of the bill. The implications of this shift will be noted in the White House and Centers for Disease Control (CDC)'s joint campaign to address the domestic epidemic, called "Act Against AIDS". This chapter demonstrates that the way in which Ryan White addresses the HIV epidemic disserves women by tying them to their role as mothers and criminalizing them for transmitting the disease. Furthermore, Ryan White also emphasizes personal responsibility for HIV testing and offers little assistance to women who use IV drugs.

In Chapter 4, I examine the Affordable Care Act and the specific ways in which gender is deployed in its discussion of HIV disease. Colloquially termed by its opposition "Obamacare", the act is a highly controversial piece of legislation that seeks to address discrimination in healthcare access across different populations in the United States. It should be noted that unlike Ryan White, the ACA is a general, domestic healthcare reform bill and thus is not meant to address the HIV epidemic specifically. The purpose of including the ACA is to show how HIV disease is portrayed in general domestic healthcare legislation, not to suggest that HIV should be at the center of American healthcare reform.

Finally, in Chapter 5, I present my alternative vision for legislation and policy concerning people with and "at risk" of acquiring HIV disease. This chapter largely draws upon Martha Fineman's development of the universal vulnerability thesis and uses her

work to introduce a new way of addressing healthcare in the United States for patients with HIV. I show how the legal adaptation of Fineman's universal vulnerability thesis would change the way in which HIV healthcare is both accessed and regulated, allowing the state to take a greater role in providing HIV healthcare for its citizens. I also offer suggestions for how to use gender in a less heteronormative way so that women with HIV disease can be better served.

CHAPTER 2: FEMINIST SCHOLARSHIP ON HIV/AIDS

Feminist scholars have studied HIV for more than three decades, responding to the developing story of the disease by tackling problem areas such as the lack of research on women with HIV, the heterosexualization of the epidemic, and the problematic use of epidemiological risk categories. Feminist legal scholars have also been discussing the gendered legal implications of HIV disease, focusing on issues such as the rights of pregnant women with HIV, the problems with mandatory testing, and the disability status of HIV patients. One important feminist theoretical perspective that has not yet been brought to bear on HIV is that offered by feminist legal theorists of vulnerability. The vulnerability perspective redefines what it means to be 'at risk' of HIV by deconstructing the traditionally vulnerable legal identity and replacing it with a universally vulnerable subject. Although vulnerability theory has not yet been applied to HIV discourse, I find it useful for critiquing the gendered implications of domestic HIV legislation and for suggesting a new framework through which the disease can be understood.

I. Feminist Theory: Gendering HIV

Feminists began paying attention to HIV in the early 1990's and have developed a wide array of critiques about HIV. I have organized them here into five main focus areas in order to illustrate how the scope of each conversation fits into the greater body of feminist theory about HIV. The five main areas discussed are the exclusion of women from public health research, feminist reactions to the heterosexualization of the AIDS epidemic, intersectional critiques of the use epidemiological risk categories, feminist post-structuralism and HIV, and the international shift in the study of HIV.

A. Feminist Critiques of the Exclusion of Women from AIDS Research

Early feminist work on HIV noted the absence of female subjects in HIV research. Ruth Faden and her research team discuss the origins and progression of biomedical research on HIV (1996). They point out that the first studies of HIV were limited to men, and it was only in 1984, three and a half years after the initial outbreak of HIV in the United States, that the CDC began investigating the disease in women. Faden et al. notes that although the CDC put forward four studies of HIV infection in women a few years after HIV was discovered, all four were in some way connected to women's roles as mothers; some investigated the effects of perinatal transmission while others studied risk factors of transmission for infected mothers to infants. None of the studies were concerned with the non-maternal roles of women in society (Faden et al. 1996, 255).

Because women were not duly included in early studies of HIV disease, not as much was known about the manifestation of HIV infection in women. Faden reviews some of the consequences of the invisibility of women in scientific research, saying, "It seems plausible

that the absence of information about the course of the infection in women has compromised the ability of medical professionals both to recognize the infection in women and to treat women known to be infected” (Faden et al. 1996, 266). Faden and her team argue that when insufficient research is conducted on women with HIV disease, the understanding of the virus’s impact on women’s bodies is doubly insufficient. Not enough is known about HIV’s manifestation in women’s bodies, which can lead to later diagnosis in women and earlier death. Faden says, “Time from diagnosis with AIDS to death is shorter for women than for men, perhaps because HIV is detected in women later in the progression of the disease” (Faden et al. 1996, 269).

Another example of the exclusion of women from AIDS research and the consequences that result can be seen in the studies done on Pre-exposure Prophylaxis, more commonly known as “PrEP”. PrEP is an oral antiretroviral medication that the CDC has found significantly lowers a person’s chances of contracting HIV disease if taken before exposure. In 2010, the CDC conducted their first successful study of PrEP, called “iPrEx”, on 1200 uninfected MSM. Half of the men were given a drug called Truvada, the most common form of PrEP, while the others were given a placebo. At the end of the yearlong study, the men who took Truvada were 44% more likely to be uninfected with a 95% confidence interval than the men who took the placebo. The CDC did not include any women in the study, but only began to test the drug on heterosexual women after these positive results of PrEP’s effectiveness in the MSM population (Michael 2010). In 2011, the CDC suspended its first and only study of PrEP among heterosexual women at risk for HIV, stating that the trials were being suspended because they would not be able to produce statistically significant results (“Results of FEM-PrEP” 2011). No further studies have been done,

leaving heterosexual women at increased risk for HIV disease with no method of prevention over which they have complete and total control.

B. Feminist Critiques of the “Heterosexualization of AIDS”

After commenting on the lack of research on women with HIV, feminists also began responding to the general public’s reaction to the ‘newly discovered’ threat of HIV to heterosexuals in the early 1990’s, terming the phenomenon “the heterosexualization of AIDS” (Patton 1994; Gorna 1996). The heterosexualization of AIDS was a response to the early epidemic that emphasized that heterosexual people could be infected with HIV; the phenomenon used women as examples of heterosexuals who could contract HIV. The “heterosexualization scare” (Gorna 1996), as some feminists have called it, began in 1987, after United States Surgeon General C. Everett Koop released the “Surgeon General’s Report on Acquired Immune Deficiency Syndrome”. The report and subsequent pamphlets on HIV that followed warned that the HIV virus could be contracted through heterosexual intercourse, and that the number of heterosexuals with the disease would steadily increase over the next few years (Koop 1987, 1). Koop’s statements inspired much media and public health discourse about the spread of HIV from ‘queers’ to heterosexuals, causing many Americans to fear the disease. Feminist theorists developed three main arguments in response to the production of a “heterosexual AIDS” discourse.

The first feminist argument against the heterosexualization of AIDS was that women were used to ‘normalize’ the epidemic, making it a ‘non-queer’ (and thus ‘normal’) disease for heterosexuals. Feminist scholar and AIDS activist Robin Gorna published an exceptional gendered critique of the HIV epidemic entitled Vamps, Virgins, and Victims: How Can

Women Fight AIDS in 1996. In her work, Gorna points out that using women to highlight the increasing spread of HIV from queers to heterosexuals assumes that all women are inherently heterosexual. She argues, "The debates about 'heterosexual AIDS' are not really asking whether heterosexuals get AIDS, but whether nice heterosexuals get AIDS – the kind of heterosexuals who warrant compassion" (Gorna 1996, 7). Gorna shows that because all women are expected to be heterosexual, which is considered 'normal', a woman who acquires HIV can transform the 'queer' disease into a 'heterosexual' infection (Gorna 1996, 7). Cindy Patton additionally argues that the heterosexualization of AIDS causes women to be seen as the 'straight exception' to the queer male body that acquires HIV disease (Patton 199, 107). Gorna says that heterosexualizing the epidemic is dangerous for women because "[it] obscures and fails women by assuming that sexuality, rather than sex or gender, is normative to most women's sense of self" (Gorna 1996, 17). In other words, women are assumed to be innately heterosexual because they are women; their sexuality comes first. The heterosexualization of the epidemic is also harmful because it does not include any mention of women who engage in non-heteronormative sexual behavior, which leads to the invisibility of lesbians in HIV discourse (Gorna 1996, 19).

The second feminist argument about the heterosexualization of the HIV epidemic is the polarization of women's sexuality into "good" and "bad" categories. Robin Gorna argues that as a result of the epidemic being heterosexualized, women are seen as either "innocent victims" of HIV or they are considered "guilty" for their own infection. Gorna illustrates her point about the polarity of women's sexuality in HIV discourse by stating, "Sexually active and proud HIV positive women are portrayed as highly culpable for their own infection. In order to acquire a life-threatening infection [a woman] must be morally suspect and

deserves to be tainted with the whore label” (Gorna 1996, 60). In other words, if a woman “actively” acquires HIV, then she must have done so through the enjoyment of sex in some form, and according to dominant norms of femininity, “innocent women” are not supposed to enjoy sex. Traditional gender roles assume that women are faithful, loyal sexual partners, and that “good women” only participate in sexual activity with one partner. The woman’s body, although the site of sexual activity, is not necessarily the site of sexual pleasure. A woman who is an active participant in her sexuality, who perhaps has multiple sexual partners or uses her body as a means of personal sexual gratification, is perceived as sexually promiscuous (Gorna 1996).

The labeling of women as “innocent” or “guilty” for their HIV infection can be easily translated to sexually active women being seen as “good” or “bad”. Women with “good” sexual practices, (i.e. behaviors that follow heteronormative expectations of female sexuality) are visible in HIV law and discourse, while women with “bad” sexuality are considered “women-who-do-not-count-as-women” (Patton 1994, 2). Cindy Patton, a feminist scholar on human sexuality, says,

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

An excellent example of Patton’s argument about “women-who-do-not-count-as-women” being invisible in HIV discourse as a result of the polarization of women’s sexuality into “good” and “bad” is the blaming of sex workers for spreading the infection. Patton argues that while the image of an innocent, “good”, heterosexual woman was used to inform the public that women could contract the disease, other women who did not meet these criteria, such as sex workers, were put to the side. Patton holds, “The underlying interest in

the ensuing of international research on 'prostitutes' was to describe how men who denied any other risk factor – 'heterosexual' men – might have become infected" (Patton 1994, 53).

In other words, sex workers were not included in HIV discourse so that laws and information would better serve them, but rather they were mentioned only so that they could be blamed for spreading HIV disease. Patton shows that their needs were left out of the mainstream HIV discourse because they were considered "women-who-did-not-count-as-women" (Patton 1994, 2). As a result of such women being left out of mainstream HIV discourse, Patton states,

Women's concerns have been erased from AIDS policy and media accounts because women are not considered to be persons. Women, and especially women's bodies, are decontextualized from women's concrete social existence, and treated as of concern only insofar as they affect men or children (Patton 1994, 107).

Patton argues that women were visible only when they were used to connect the 'gay disease' to the presumed heterosexual, "normal" (read: non-gay) population (Patton 1994).

The third and final argument that feminists brought against the heterosexualization of AIDS was that the phenomenon caused women to be seen as a public health threat to their (presumably male) partners and children. Cindy Patton has termed this phenomenon the vagina/uterus dichotomy (Patton 1994, 107), saying, "To put it bluntly, women are either vaginas or uteruses, and curiously, never both at the same time" (Patton 1994, 107). Tamsin Wilton agrees with Patton that women with HIV are seen as a public health threat to men and children. Her book EnGendering AIDS: Deconstructing Sex, Text, and Epidemic is one of the most widely regarded queer theory texts on HIV, and it also acknowledges the vagina/uterus dichotomy. Wilton argues, "AIDS discourse generally constructs a familiar model of woman-as-risk-to-man, both sexually and maternally. Prostitutes in particular, and women generally, are described as 'reservoirs of infection' or 'an index to the spread of

heterosexual AIDS' (Wilton 1997, 69). The vagina/uterus dichotomy acknowledges women in HIV discourse only in their roles as 'irresponsible' vectors of the disease.

C. Feminist Intersectional Critiques of Risk and Epidemiological Categories

The third major strand of feminist theorizing about HIV discussed problems with the epidemiological categories of risk that were used to study the disease and instead advocated for a more intersectional approach to HIV. The theory of intersectionality can be useful when applied to HIV, as it can expand the axis of analysis to include identity categories such as race/ethnicity, gender, sexual orientation, and physical ability. Early scholars such as Joe Rhatigan pointed out that the risk categories focused only on the identity category of sexuality, resulting in an emphasis on individual behavior, which obscured the racialized and classed dimensions of HIV (Rhatigan 1996). Shari Dworkin further argues that a single dimensional analysis of HIV can hold consequences for men and women, because it does not accurately reflect a person's risk for contracting the disease. Dworkin shows that the way HIV is epidemiologically studied implies that individuals possess only a singular identity within society that predisposes them to HIV disease, such as being a man who has sex with men (MSM) or an African American. Dworkin argues that because individuals have multiple, intersecting experiences within society that make them more vulnerable to HIV, these factors should be accounted for in the study of the disease (Dworkin 2005, 618). When the multiple identities of women are not considered in their risk for acquiring HIV, the actual risk that their identities pose to their likelihood of acquiring the infection cannot be fully known.

An intersectional approach to HIV disease helps to address the problems of uni-dimensional epidemiological categories by studying the ways in which multiple layers of a person's identity interact to create a systems of oppression (Simien 2007). Feminist theorist Evelyn Simien defines intersectionality as,

Firmly rooted in an experience-based epistemology, it encompasses perspectives that maintain that such identity categories as gender, age, race, ethnicity, class, and sexuality are mutually constituted and cannot be added together. Intersectionality places special emphasis on the simultaneity of oppression and stresses the need to move beyond simple, additive models [of oppression] (Simien 2007, 265).

Intersectionality essentially shows that one cannot simply add up the number of oppressions that a person faces in order to assess her/his risk of acquiring HIV disease, but rather these categories of identity are constantly interacting with each other to produce vulnerability to infection.

The theory of intersectionality was quickly applied to HIV discourse as a way to show how women, and especially African American women, were vulnerable to HIV disease. A concrete example of the use of an intersectional approach to study risk for HIV disease is the multi-dimensional and complicated relationship of poverty, drug use, racism, and HIV. Intersectionality theory can be used to better understand why African American women have the highest prevalence of HIV disease of any female group in the United States. Feminist theorist Diane Lewis's article "African American Women at Risk", published in 1995, uses an intersectional approach to illustrate how poverty, discrimination, and substance abuse can cause high rates of infection in African American women. Lewis argues that intersectional factors work together to produce a culture where HIV thrives. She cites an example that HIV is spread rapidly in poor black communities with high rates of drug use because black men make a living off of selling drugs. As a result, black women

are more likely to be exposed to HIV either through the use of IV drugs or by sleeping with a man who has HIV. As a result of poverty and high rates of drug use, women in poor African American communities are much more likely to have sex with a drug user than white women (Lewis 1995, 61). Thus, Lewis demonstrates how multiple, intersecting factors of identity work to subject certain people more easily to HIV disease.

Like Lewis, Cathy Cohen also discusses how intersecting identities create vulnerability to HIV disease. In her 1999 book The Boundaries of Blackness: AIDS and the Breakdown of Black Politics, Cohen discusses the way in which a person's multiple and intersecting identities allow her/him access to specific systems of power. Cohen argues that no single category of identity, such as race, makes a person more likely to acquire HIV disease than another category of identity. In other words, African American women did not acquire the disease at a greater rate than white women simply because they were African American. Rather, Cohen shows that it was a multitude of intersecting oppressions in the lives of African American women that allowed them to be more likely than white women to contract the disease. At the time of the book's publication, Cohen's ideas are somewhat contrary to mainstream public health research, which suggests that persons of certain (usually racial) identity categories were are likely to acquire HIV disease than others only because of their race.

D. Post-Structuralist Analysis of HIV Discourse

Although some feminist scholars have continued to focus on intersectionality theory's influence on HIV disease, a post-structuralist feminist theory about HIV has also developed. Post-structuralist feminist scholars study what it means to have HIV and how

our knowledge of HIV produces diseased female bodies. Feminist Susan Craddock studies the responses of governments, organizations, and communities to infectious diseases, including HIV. Craddock uses some of Donna Haraway's work in science studies and combines it with a post-structuralist argument to illustrate that the "cultural framing" of the HIV epidemic – or where it is located in the world and who can become infected – produces a certain identity and a specific type of diseased body with HIV (Craddock 2000, 159). Craddock holds that medical institutions produce a certain type of HIV discourse, which influences what is scientifically researched, which impacts what can be known about HIV. She argues, "The impact of these principles influences the kinds of 'facts' sought in medical research, and consequently determines the kinds of knowledge produced and the types of bodies prescribed as dangerous" (Craddock 160, 2000). She further argues that the formation of identities created by the medical discourse of HIV impacts the epidemiological interpretations of research and thus the legislation that results from such research.

While studies of HIV help produce a certain type of knowledge, the process of defining HIV disease itself creates a limited framework for what can be known and understood about the disease. Feminist theorist Marsha Rosengarten uses a post-structuralist analysis to show how knowledge about HIV disease is created through its definition. She argues that language and the act of speaking about HIV generate a specific set of "facts" about it, which influences what can be known and understood about the disease itself. For example, the CDC's definition of "AIDS" did not formally include symptoms specific to women until 1993. Prior to editing the definition, symptoms of HIV common to women, including pelvic inflammatory disease and recurring sexually transmitted infections were not considered to be symptoms of an HIV infection (Dworkin

2005). Because the CDC failed to include HIV symptoms present only in women, the early definition of HIV affected what could be known about the disease's manifestation in the female body. The parameters for medically diagnosing an HIV infection limited the scope of the disease at the expense of women. Through her post-structuralist analysis, Rosengarten effectively argues that knowledge about HIV is both socially constructed and socially situated. Her work supports Craddock's argument that HIV is culturally and socially situated, because when HIV is defined, this too becomes part of the social construction of the disease (Rosengarten 2004).

The metaphors that are used to talk about HIV disease are also part of the social construction of HIV, according to feminist author Susan Sherwin. Sherwin argues that HIV discourse is riddled with metaphors that each support different strategies for prevention. For example, Sherwin shows that AIDS itself is a metaphor of HIV, as it often represents a variety of illness and groups. Sherwin argues that 'AIDS' can be seen as the modern day Bubonic plague, a disease of the poor, retribution from God, and/or a chronic disease. AIDS is thus a metaphor in the sense that it can represent a certain phenomenon or even a certain group of people (Sherwin 2001, 333). Sherwin further argues that many metaphors exist in the discourse of HIV prevention, saying that many of these metaphors are harmful to women.

Sherwin applies post-structuralist feminist theory to HIV in order to talk about the many metaphors within HIV prevention, arguing that the way prevention is promoted has a gendered impact on groups considered to have the disease. She says,

"Many of the metaphors that are being promoted to understand AIDS threaten to deepen existing forms of oppression against women as well as against gay men and people of color, so it is especially urgent that we consciously seek out and endorse alternative

metaphors that are more likely to help to reduce some forms of oppression” (Sherwin 2001, 333).

Sherwin holds that the description of someone who is HIV infected can serve as a metaphor for a person living with AIDS. She says that these metaphors, which are used to understand HIV disease, are harmful because they are often gender ignorant. The metaphors we use to understand HIV are important because they affect the way in which HIV prevention is promoted and to whom prevention messages are given, which in turn impacts the spread of the disease. Sherwin warns against prevention methods that single out certain groups of people or that can be construed as oppressive to non-white males (Sherwin 2001).

E. Looking at International Dynamics of HIV

Most recently, feminist theorists of HIV have shifted their analyses to the international level. This literature illustrates the important point that HIV is both culturally and geographically situated. In 2005, during the presidency of George W. Bush, Congress passed a law that most people refer to as “PEPFAR”, or the President’s Emergency Plan For AIDS Relief” (PEPFAR 2005). PEPFAR was not warmly welcomed by American feminists, public health researchers, or AIDS activists, as it did not provide funding for family planning or abortions and promoted abstinence as the key to preventing HIV (Saunders 2004; see also Stoebenau 2009).

Feminist theorists have continued to question and probe the gendered effects of HIV, in the midst of the new focus on the disease. Feminist Kirsten Stoebenau has offered critiques of public health discourse as well as legislation governing international HIV funds. Stoebenau uses the idea that HIV produces bodily identities in order to argue against the use of epidemiological categories to study the disease. She cites examples for her argument

by saying that many people abroad who exchange sex for money or other commodities (drugs, food, etc.) would not consider themselves prostitutes or sex workers. Thus, when studying HIV disease, it is important to consider the geographical construction of identities on the subjects being studied (Stoebenau 2009; see also Saunders 2004).

In the last several years, HIV has come to be connoted as a foreign infection that does not really affect the presumably good people of the western world. Feminists have critiqued the shift from domestic to international HIV discourse in recent years, saying that President Bush was playing the masculine, western role of protector and that he promoted support for his legislation through the use of “the politics of compassion” (Zivi 2007).

Karen Zivi argues that after legislators finally realized that the international HIV epidemic was affecting women and children at alarming rates, they began to create ‘compassionate’ legislation, such as PEPFAR, to address the disease. Zivi argues that legislation like PEPFAR is problematic not only because of its heavily conservative influences but also because it acts condescendingly (read: ‘compassionately’) towards ‘foreigners with AIDS’ (Zivi 2007, 43). Zivi says,

[Compassion] perpetuates inequality in part by basing a responsive action on an assessment of worth: if someone is not to blame for his or her suffering, then he or she is worthy of compassion. In the context of AIDS policymaking, the assessment of women’s worthiness turns on evidence of a self-sacrificing maternalism, a requirement, I contend, that makes it difficult, if not impossible, to place certain concerns on the policy agenda (Zivi 2007, 43).

So the politics of compassion can be a problem because it allows western power-holders, like President Bush, to judge who is ‘worthy’ of receiving compassion. Zivi further argues that President Bush collected money for HIV because he played the role of a masculine protector, giving money and aid to all of the ‘foreigners’ with HIV who were presumed to be unable to help themselves.

F. The Use of Feminist Theory

Feminist theory, be it focused on the heterosexualization of the AIDS epidemic, intersectionality theory, post-structuralism, or international HIV, has developed over the course of the last 30 years and can be used to help navigate the complicated and often controversial issues surrounding this disease. The work of the feminist scholars mentioned in this section, and especially the arguments of Cindy Patton, Robin Gorna, Shari Dworkin, and Diane Lewis, will be used in Chapters 3 and 4 to critique the way in which the ACA and Ryan White are deploying gender and sexuality and how this affects women with HIV disease. The arguments of these authors are especially helpful in pointing out the consequences of the legislation's problematic deployment of traditional gender roles and sexual norms for women with HIV.

III. Feminist Legal Theory and HIV: Fighting for Women's Rights

Like theoretical feminist scholarship on HIV disease, conversations within the realm of feminist legal theory have changed over the past three decades, in the effort to develop legal arguments that are more inclusive of the needs of women with HIV. In my reading of feminist legal theory about HIV, I found three major frameworks being used to analyze the legal aspects of HIV disease: a gender-based framework, a human rights framework, and a disability framework. Although there are other frameworks used to theorize legal problems associated with HIV, such as speech, property, and privacy (Hunter 1993; Matthew 2010), I will limit my analysis to the aforementioned three, as they are some of the most relevant

for my analysis of the ACA and Ryan White. Feminist legal theorists have debated whether or not HIV constitutes a legal disability, the rights of women and fetuses in regards to mandatory testing, the legality of mandatory HIV testing, the criminalization of persons with HIV disease, and the gendered legal barriers to care faced by people living with HIV. I will briefly explore how the three frameworks look at HIV to show how legal conversations about HIV disease have evolved in the past three decades. I argue that rather than being isolated from each other, these conversations could benefit from being brought together, as they each add a meaningful dimension to feminist legal theory about HIV.

One of the first major feminist frameworks to be developed for the legal analysis of HIV disease was gender-based. In 1994, legal theorist Mary Anne Bobinski wrote an influential article on the legal regulation of HIV disease, much of which is still relevant today. Bobinski explores whether or not gender has any relevance in the legal regulation of HIV, concluding, "Gender-based analysis is a useful tool for understanding and critiquing several aspects of the legal system's response to HIV infection. However, gender analysis alone is inadequate to determine appropriate criminal or tort policies toward HIV transmission" (Bobinski 1994, 9). Bobinski outlines several ways in which a gender-based analysis can be useful for critiquing legal theory about HIV, namely that it can be used to identify the discriminatory consequences of facially gender neutral policies regarding HIV. For example, Bobinski argues that gender differences are present in the likelihood of transmission of HIV as well as in the study of HIV. Certain behaviors hold different risks for men and women, and women are often underrepresented in research studies.

As an example of the efficacy of a gender-based legal analysis of HIV, Bobinski looks at the gendered aspects of criminalization for the transmission of HIV. The issue of

criminalization is very problematic for Bobinski, because the biological risks of acquiring and transmitting HIV disease are very different for men and women. For example, when having sex with an infected partner of the opposite sex, a woman is more likely to acquire HIV disease from a man than a man is from a woman, simply because the surface area in a woman's vagina is larger than the surface area of the penis. Bobinski argues against facially gender-neutral laws that criminalize people for transmitting HIV disease, saying that these laws do not take into account the biological differences between men and women, nor do they account for the issue of consent. Ultimately, Bobinski states that a more intersectional approach to HIV law must be used, because claiming that a law is discriminatory on the basis of gender is very difficult to substantially prove in court (Bobinski 1994).

While the facially gender-neutral policies present in the law do not account for the biological differences in transmission, they also do not leave room for individual patient autonomy. Legal theorist Margo Kaplan uses a gender-based analysis of HIV law to discuss how criminalization for transmission can rob women of their own bodily autonomy, which is compromised by policies that do not account for gender differences in transmission. She argues that because of the Supreme Court's gender-ignorant ruling of *Gonzalez v. Carhart* in 2007, pregnant women with HIV disease could be forced to undergo unwanted medical procedures in order to better protect their fetus. If pregnant women refuse such procedures, they could be criminalized for transmitting the virus. However, Kaplan outlines the reasons why pregnant women with HIV disease may not wish to undergo certain medical procedures, like Cesarean sections or antiretroviral therapy (ART) (2008). She says,

[ART] and Cesarean surgery have numerous risks and side effects. The side effects of ART range from unpleasant to life threatening, including: nausea, vomiting, diarrhea,

neuropathy, impaired functioning of the vital organs, bone marrow suppression, damage to the reproductive system, and the increased risk of heart disease. Patients taking ART may also develop resistance to them, which could reduce a woman's treatment options when [ART] is needed for her own health (Kaplan 2008, 185).

In addition, some pregnant women may not want to have a Cesarean section because of additional medical bills, scarring, fear, or because of their religious or personal beliefs about natural/vaginal births (Roth 2000). Kaplan's argument about how HIV law can be used to criminalize pregnant women with HIV is a perfect illustration of how a gender-based approach to HIV legislation can be effective in pointing out areas of the law that do not consider or respect women's needs and desires.

The second major feminist legal framework used to critique HIV legislation was human rights-based. Beginning in the late 1990's, some feminists began to argue that a human rights-based analysis should be added to a gender-based analysis in order to better conceptualize HIV law. Authors such as Aziza Ahmed (2009), Jennifer Sinton (1997), and Vicci Tallis (2000) have pointed out both the strengths and weaknesses of the human rights framework for critiquing HIV. Legal scholars Aziza Ahmed et al. argue that a human rights approach can be effective when discussing the gendered legal aspects of HIV. In her article "Protecting HIV-Positive Women's Human Rights", Ahmed and her team call for a better human rights framework to be adapted in the National HIV/AIDS Strategy for the United States, the first national HIV plan released by President Obama in 2010. The strategy outlines goals for reducing the number of domestic infections, curbing discrimination against Americans living with HIV, and increasing access to care and improving the health outcomes of people with the disease (National Strategy 2010, 10-11).

Ahmed et al. argues that treatment of people with HIV has been institutionalized through criminalization of sexual behaviors and the elimination of patient consent in some

circumstances of mandatory testing (Ahmed et al. 2009, 127). Her team reports that over half of the individual states in America have laws that criminalize sexual behavior of people with the disease, noting the gendered consequences of such criminalization for men and women. Ahmed additionally calls for the elimination of persuasive/coercive HIV testing, noting that it can be detrimental to women and scare them away from medical facilities altogether. Ahmed argues that an increased focus on human rights in the National HIV/AIDS Strategy will have better results for women and will help fight against the institutionalized reactions to HIV, such as criminalization and mandatory testing (Ahmed et al. 2009).

While some legal scholars argue that a human rights-based approach to HIV can be effective, others such as Jennifer Sinton and Vicci Tallis hold that it is insufficient because it inevitably dissolves into a debate over whose human rights are more important. For example, Sinton argues shows that a human rights framework is not useful for critiquing the debate over the legality of mandatory testing of pregnant women and children with HIV disease. She says that talking about human rights often dissolves the discussion into an endless argument of women's rights versus fetal rights. Sinton states, "Both proponents and opponents of mandatory testing use the language of rights to legitimate their arguments and appeal to common sense" (Sinton 1997, 6). The 'woman v. child' dichotomy does little to solve anyone's problems, because it does not show how women are adversely affected by mandatory testing, and it also turns them against their children. Sinton additionally argues,

Rights discourses focus the public's attention on abstract notions and rhetoric and construct an opposition between women and their children. Conferring a right becomes an end in itself. Rhetoric creates the impression that the mandatory testing issue will be solved once we determine whose rights are more important (Sinton 1997, 8).

Thus, focusing on human rights alone does not produce an adequate framework for analyzing legal issues of HIV because it ignores women's unique position as child bearers and mothers and polarizes arguments about fetal/maternal rights.

In addition to creating battles over whose rights are more important and ignoring women's positions as human beings as well as mothers, the rhetoric of human rights is often critiqued as inherently masculine. When 'human rights' are synonymous with 'men's rights', this legal framework does little to help HIV positive women gain the legal rights they deserve. Vicci Tallis speaks out against the use of a human rights framework to analyze HIV. Tallis holds that one of the major impediments to HIV/AIDS prevention is gender inequality, and that the use of a human rights framework to combat gender inequality is largely ineffective. Tallis argues that the idea of 'human rights' itself is a very masculine concept that assumes that men are the social norm, ignoring women's social position and rendering them invisible. In other words, because women and men are not socially equal, the rhetoric of human rights focuses on men's rights by default and only works to label women as 'other' (Tallis 2000).

The third major approach of feminist legal theory to HIV is a disability framework. In U.S. law, the disability framework was developed largely after the passage of the Americans with Disabilities Act of 1990 and the Amendment Act of 2008. The debate over whether or not HIV constituted a legal disability flared during *Bragdon v. Abbott*, an influential case adjudicated by the Supreme Court in 1998. The defendant, Sidney Abbott, a woman with HIV disease, claimed that her dentist, Dr. Randon Bragdon, was discriminating against her because he refused to fill a cavity in her mouth. Ms. Abbott signed a form stating that she had asymptomatic HIV, and Dr. Bragdon refused to treat her unless she paid for

the use of a hospital facility where he could perform the procedure. Ms. Abbott supported her argument of discrimination by using the Americans with Disabilities Act, claiming her HIV status constituted a disability because it “severely limited” her ability to reproduce. The Supreme Court eventually ruled in Ms. Abbott’s favor, stating that a physician could not refuse service to a client on the grounds of an HIV infection. However, the court avoided the question of whether or not HIV constituted a disability, and it also allowed for further stigmatization of women with HIV disease who chose to have children (Keels 2010).

Bragdon resulted in severe consequences for women’s health because the court’s ruling deepened the disagreement over when and under what conditions HIV could be considered a disability. In light of *Bragdon*, several feminist legal theorists, including Lisa Keels, Ashley Southerland, and Timothy Frey have argued over the efficacy of a disability framework to legally conceptualize HIV disease. Lisa Keels was disturbed with the outcome of the *Bragdon* ruling, arguing that it jeopardized the future of women’s reproductive health rights. Keels argues that if a woman with HIV wants to have a baby, she could be scorned and looked down upon for taking the chance of transmitting the virus to her fetus. She notes that *Bragdon* was ironic, because while it protected a woman’s right to healthcare access, it also “established a framework under which medical professionals could discriminate against women with HIV/AIDS in the context of reproduction” (Keels 2010, 391).

Legal scholar Ashley Southerland argues that the current disability framework is insufficient for people with asymptomatic HIV disease, because in order to receive legal protection, it is first necessary to prove that one is ‘substantially limited in one or more life activities’ (Southerland 2010, 838). If one cannot prove that HIV significantly limits one or

more life activities, then the case cannot be backed by the ADA; thus, if a woman with a low viral load who shows no physical symptoms of an HIV infection needs legal protection, perhaps to access housing or meet her healthcare needs, she cannot be protected under the ADA because she would not be legally considered to have a disability. Thus, Southerland illustrates the ambiguities present in the ADA and the resulting consequences for people with HIV. Southerland additionally notes that the Affordable Care Act, the most recently passed domestic healthcare legislation, is “riddled with the same substantive ambiguities that plagued [its] statutory predecessors, and ultimately [leaves] asymptomatic HIV/AIDS sufferers unprotected from health status-based discrimination” (Southerland 2010, 836). Southerland calls for a framework of disability that is more inclusive of people who are faced with health problems.

Timothy Frey also agrees with Southerland that the outcome of new legislation like the Affordable Care Act is uncertain because of ambiguities and holes in the legislation. Frey argues, “Because the circuit courts cannot agree on a proper reading of the ADA, health insurers and beneficiaries remain uncertain of their rights and responsibilities, and the law continues to allow for discrimination against individuals based upon physical disabilities” (Frey 2010, 643). Frey, like Southerland, is arguing that the current legal framework of disability in the United States is inadequate because it gives rights to some disabled persons at the expense of the rights of others, isolating women who need care. These authors all advocate for a legal framework that is more inclusive of the needs of women with HIV, regardless of their current health status. The ambiguous use and interpretation of disability legislation in addition to women’s ability to recognize their own

legal needs all encourage a more clear and concise definition of disability and a more inclusive disability framework.

While the feminist legal frameworks on HIV offer a way to better conceptualize the disease in a way that includes women, an intersectional analysis could be added to the gender-based legal analysis of HIV, resulting in a way to better address the legal issues of criminalization. The facially gender neutral policies that can be used to criminalize pregnant women with HIV disease (Bobinski 1994), for example, would be forced to recognize the multitude of factors that contribute to a pregnant woman's decision to have a medical procedure. Currently, legal scholarship focuses only on the agency of pregnant women and their right to make their own decisions (Sinton 1997; Ahmed et al. 2009); however, I argue that feminist legal theorists could use the idea that women have multiple, conflicting identities and oppressions to strengthen their argument. While feminist theory on HIV and feminist legal theory can be quite useful for critiquing domestic HIV legislation, these two bodies of scholarship are still inadequate for fully analyzing Ryan White and the Affordable Care Act. I argue that the analysis would be stronger if a better approach to domestic HIV legislation – one that is fully inclusive of women's needs – were considered.

IV. Vulnerability Theory: A New Feminist Legal Framework for HIV Law

Although legal frameworks of gender, human rights, and disability have all been used to assess and critique domestic HIV legislation, I argue that these approaches to HIV law are ultimately insufficient. The use of Martha Fineman's universal vulnerability theory to formulate laws about HIV disease would be more effective than a framework of gender,

human rights, or disability, largely because the theory of vulnerability addresses the universal and the gendered aspects of HIV disease simultaneously.

Before proceeding with a discussion of universal vulnerability theory, it is important to note the different connotations of the word ‘vulnerability’, each of which is specific to a different academic conversation. The traditional meaning of the word ‘vulnerable’ is “capable of or susceptible to being hurt or wounded” (Merriam Webster Online 2012). In the ACA and Ryan White, vulnerability is used in this traditional way; according to the law, a person is vulnerable to HIV disease because of his/her specific life circumstances that render him/her ‘susceptible to being hurt’. Some feminists refer to this traditional use of vulnerability as the “vulnerability paradigm” (Dworkin 2005; Higgins et al. 2010). For feminist theorists, and specifically those with an intersectional approach to vulnerability, a person is vulnerable to HIV disease in this traditional sense because of the intersecting oppressions that result from conflicting identities (Dworkin 2005; Higgins et al. 2010).

Feminist authors Jenny Higgins and Peter Aggleton argue that labeling women as vulnerable to HIV disease removes women’s sexual autonomy and assumes that all women are powerless to prevent the spread of HIV (Higgins et al. 2010). They also discuss how that terming certain populations as ‘vulnerable’ to HIV disease implies that other groups are ‘invulnerable’ (Higgins et al. 2010; Aggleton 2004). In Chapter 4, I will demonstrate at greater length the law’s use of traditional vulnerability to describe people with HIV disease and how this use is detrimental to women with HIV disease.

In contrast to a traditionally understood idea of vulnerability as it affects a specific group of people, universal vulnerability theorists conceptualize vulnerability as a condition that affects all people. Universal vulnerability theorists believe that as human beings, all

people are vulnerable to viruses and bacteria that threaten to diminish their health status (Fineman 2008). This idea emerges most clearly in feminist legal theorist Martha Albertson Fineman's groundbreaking 2008 article "The Vulnerable Subject: Anchoring Equality in the Human Condition". The assertion of Fineman's universal vulnerable subject into HIV law would help feminists address the dangers of labeling women particularly 'vulnerable' to HIV disease. In her work, Fineman introduces the idea of universal vulnerability, arguing that all human beings are vulnerable to their circumstances in the surrounding world.

Fineman states,

"Vulnerability is – and should be understood to be – universal and constant, inherent in the human condition ... it is a "post-identity" inquiry in that it is not focused only on discrimination against defined groups, but concerned with privilege and favor conferred on limited segments of the population by the state and broader society through their institutions" (Fineman 2008, 1).

Rather than assuming that legal subjects are independently successful and do not require the assistance of the state, Fineman argues that the law should recognize the universal vulnerability of all human legal subjects (Fineman 2008, 1).

Fineman's idea to assert a vulnerable legal subject is in direct contrast to the current neoliberal subject to whom domestic HIV law is currently addressed. According to Australian post-structuralist feminist theorist Bronwyn Davies, the neoliberal legal subject can be described as "built on a radical reconception of an individualized, competitive, free and responsabilized subject, a subject that understands itself, in liberal humanist terms, as free and in control of itself and responsible for its own fate" (Davies et al. 2006, 88). This self-aware, self-serving subject is very present in our current laws about HIV disease. Although addressing a self-sufficient, self-responsible legal subject decreases the state's responsibility to participate in and regulate the health of its citizens, the fact that the law

addresses a neoliberal subject does not benefit women with HIV disease because the neoliberal subject does not represent her needs or the needs of others. Feminist psychologist Judith Jordan states, "In a dominant, Western culture that celebrates strength in separation and holds unrealistic expectations for independent, autonomous functioning, vulnerability is seen as a handicap" (Jordan 2008, 209). Replacing this neoliberal subject with a more universally vulnerable subject would enable the law to better serve a greater number of people with HIV.

Fineman's ideas about vulnerability could easily transform the way in which Americans conceptualize legal subjects. Feminist legal scholar Ani Satz has already introduced this account of universal vulnerability to health and disability law (Satz 2008; Satz 2009). Her work argues that disability is a universal vulnerability to which all people are subjected, at least in some form. The argument that she makes against the American's with Disabilities Act of 1990 replaces the neoliberal subject with the vulnerable subject. Satz states, "Those who require additional health care, wage supports, or environmental adaptations to function are disadvantaged by a system that views their needs as exceptional, rather than as a manifestation of the human condition" (Satz 2009, 526). Her argument is clearly also applicable to the American healthcare system.

Like Satz regarding disability law, I am arguing that Fineman's work can and should be applied to HIV law. Instead of pointing out, as many epidemiologists have done, that certain groups of people are more 'vulnerable' to HIV than others, Fineman's thesis argues against the use of vulnerability as an identity. This requires removing all assumptions about the race, ethnicity, gender, sexuality, class, and socio-economic status of people who are traditionally considered to be 'vulnerable' to HIV. The assumptions about which

identities are most vulnerable to HIV are then replaced with the post-identity idea that all people are equally vulnerable to HIV but that certain social and institutional inequalities predispose some groups to the disease more frequently than others.

Fineman argues that the assertion of the vulnerable subject in the law would allow the state to play a more active role in the regulation of society's institutions. She states that the assertion of the vulnerable subject calls for a "responsive state" that pays close attention to the institutional distribution of privilege that each person uses to protect her/himself from vulnerability. She says,

My ultimate assertion is that true equality of opportunity carries with it the obligation on the state to ensure that access to the societal institutions that distribute social goods, such as wealth, health, employment, or security, is generally open to all, and that the opportunities these institutions provide are evenly distributed so that no persons or group of persons are unduly privileged while others are disadvantaged to the extent that they can be said to have few or no opportunities" (Fineman 2010, 2-3).

Fineman shows that equal opportunity does not necessarily mean total and complete equality, such as one would find under an authoritarian state; however, the universally vulnerable legal subject does allow the state to step in and regulate the institutional distribution of privilege when one group is being privileged over another. In this way, universal vulnerability theory, as Fineman is applying it to the law, could be useful for ensuring that patients with HIV disease have adequate access to healthcare and are able to live better, healthier lives.

V. Conclusion

As I have demonstrated in this chapter, conversations about HIV within feminist theory on HIV and feminist legal theory have all changed dramatically over the past thirty years. I am arguing that they can be used together in order to offer a more interdisciplinary,

intersectional feminist view of HIV legislation. Furthermore, I argue that adopting a feminist universal vulnerability approach can strengthen feminist critiques of domestic laws governing HIV disease. In the next two chapters, I will discuss the ways in which this interdisciplinary, intersectional feminist analysis can be used to critique the deployment of gender in the Ryan White CARE Act of 1990, the Treatment Extension Act of 2009, and the Affordable Care Act of 2010. I will also draw from vulnerability theory to argue that a vulnerable legal subject should be placed at the center of HIV legislation.

CHAPTER 3: "INFANTS AND WOMEN, ETC": THE INVISIBLE OTHERS OF THE RYAN WHITE CARE ACT

I. Introduction to the Ryan White CARE Act

In this chapter, I explore the ways in which the Ryan White CARE Act deploys traditional gender roles and sexual norms while trying to afford care to individuals and families with HIV disease. I also discuss how the Act Against AIDS Campaign, which is partially funded through the Ryan White Treatment Extension Act of 2009, uses a problematic and gendered rhetoric of personal responsibility to further marginalize people living with HIV. By applying feminist theory on HIV, feminist legal theory, and universal vulnerability theory in a critique of this legislation, I provide an intersectional and interdisciplinary feminist analysis of Ryan White. Although Ryan White provides a great deal of money for the prevention, treatment, and study of HIV every year, it often does so at the expense of those with the disease. People with HIV can be criminalized, stigmatized, and marginalized by the law, while gender and sexuality are deployed so as to tie women to their roles as mothers and render invisible the needs of gay men and women. I will first

offer a brief overview of the Ryan White CARE Act and will then move on to a feminist critique of how the law deploys gender in this piece of domestic HIV legislation.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is a piece of legislation named after a young man who died in 1990 from complications related to acute HIV infection. The Act was drafted and signed in 1990 and is designed specifically for the purpose of providing grant money to fund health services and research for HIV disease. The Act's overall goal is to "improve the quality and availability of care for individuals and families with HIV disease" (Ryan White 1990, 1). Ryan White is made up of four titles, each of which allots grant money to specific individuals and entities for HIV care and research. In 1990, the bill authorized over \$230 million for domestic HIV prevention and treatment (Ryan White 1990, 31); by 2009, when President Obama signed the Ryan White Treatment Extension Act, this number had reached over \$2.1 billion (Blendon et al. 2011)

Each year, the United States government spends approximately \$500 million on domestic HIV prevention, care, and research for the over 1 million Americans infected with HIV, most of which comes from Ryan White (National Strategy 2010, 12)¹. Although the United States has spent billions of dollars to help improve the lives of Americans with HIV, the money provided is not sufficient to meet the demand for services. For example, about a third of Ryan White's money goes to fund the AIDS Drug Assistance Program (ADAP), which provides funding for low-income individuals with HIV disease to have access to highly active antiretroviral therapy (HAART) ("The Ryan White Program" 2012). In the state of Georgia alone last year, however, there were over 1400 people on the waitlist to

¹ The cost of treating one patient with HIV for a full year was approximately \$10,800 in 2010 (www.cdc.gov/hiv), and the lifelong treatment cost for one individual with HIV has been estimated at \$355,000 (National Strategy 2010, 19).

² At the end of 2009, the CDC estimated that there were about 56,000 new infections of HIV disease every

receive ADAP funds, despite the fact that the state spent \$53.5 million in fiscal year 2011 on HAART (“HIV Care Program” 2012). Although Ryan White does provide money for research and treatment of patients with HIV disease, it could do more to improve the lives of these patients. Ryan White is providing a large sum of money for HIV causes, but I will demonstrate that this law does so only when gender roles and sexual norms are performed “appropriately” and the heteronormativity of society remains unchallenged.

II. “Infants and Women, Etc.”: Funding Support Services and Research for the ‘Others’

One of the biggest problems with Ryan White is that the language of the law treats men as the primary subjects, allowing everyone else to be seen as second-priority ‘others’. For example, Part of Title II of Ryan White sets aside money for individual states to improve the quality and availability of healthcare for their citizens with HIV disease. A subsection in this title outlines the two acceptable uses of the grant money: the first use is found in a subsection titled “In general” and gives a broad list for general funding. The second use is found in a subsection entitled “Infants and Women, Etc.” and reads, “A state shall use not less than 15 percent of funds allocated under this part to provide health and support services to infants, children, women, and families with HIV disease” (Ryan White 1990, 12). In the 55 pages of the original draft of Ryan White, the word “women” is used a total of nine times. However, in eight out of these nine mentions, women are grouped together with infants and children through the repetition of the phrase “infants, women, and families with HIV disease” (Ryan White 1990, 12). The word “men” is never mentioned in the document, and men as a general group are never directly referred to in all of the 55 pages. While some might praise the law’s special recognition of women, the quote above

illustrates perfectly through the use of traditional gender roles and sexual norms that the law is addressing a male subject.

In addition to the “Infants and Women, Etc.” subsection, the Ryan White CARE Act also addresses male subjects by distinguishing men from “infants, women, and families with HIV disease” (Ryan White 1990, 12). In Title IV, “General Provisions, Reports, and Evaluations”, the law is again stipulating how much grant money can be allotted for patient care and to whom it can be given. In this title, the federal government stipulates conditions under which it will give money to community health centers and medical facilities that provide primary healthcare services to the public, specifically for research on how to better treat HIV disease. The law states that priority for receiving the grant money will be given to institutions whose focus is on pregnant women with HIV disease and their children. The law reads, “The secretary may not make a grant under subsection (a) unless the health facility operated by the applicant for the grant serves a *significant number* of pediatric patients and pregnant women with HIV disease” (Ryan White 1990, 43) [emphasis added]. Unfortunately, the law does not give a definition of what constitutes a “significant number” of clients; there are no specifications for how many children and/or women must be included, and there is also no monetary encouragement for the research of women with HIV who are not mothers.

By treating women as a special, vulnerable group, rather than addressing men and women together, Ryan White confirms the fears of the many feminists who have argued that HIV is yet another way in which women have been turned into insignificant others and made invisible by the law (Patton 1994; Gorna 1996; Wilton 1997). The fact that men are never mentioned as a distinct group within Ryan White is quite telling of the assumptions

about whom the law is addressing. Although some might suspect the law is leaving men out, I argue that a distinct group of 'men' is never directly mentioned because men are assumed to be the subjects of the law. In other words, the law does not need to single men out, because it is assumed that men are always already the subjects being addressed. With the added "etc.", anyone can be placed into this category of seemingly second priority, and the word leaves open the possibility that there remain third and fourth ranked priorities of people that are not even mentioned but are included through the simple abbreviation.

As a consequence of the law's focus on male subjects, Cindy Patton argues that women have been othered and left out of HIV discourse altogether unless they are mothers. Patton states, "Women's concerns have been erased from AIDS policy and media accounts because women are not considered to be persons. Women, and especially women's bodies, are decontextualized from women's concrete social existence, and treated of concern only insofar as they affect men or children" (Patton 1994, 107). Patton's argument about the invisibility of women in HIV legislation is clearly illustrated through Ryan White. The legislation mentions women only in respect to their role as mothers and repeatedly uses the phrase "infants, women, and families," which leaves women's other roles in society unacknowledged.

Faden's argument about the lack of research for HIV positive women is also clearly illustrated by Ryan White, which mandates that only 15% of a large portion of research money *must* be used to study women and children with HIV, meaning that 85% could conceivably be left to support men. The CDC estimates that in 2011, about 27% of new infections in the United States were among women and 1% were among children. So even though men make up just 72% of all new infections in the United States ("Basic Statistics"

2009), they can receive up to 85% of all the money for research! Although some research studies can be beneficial to pregnant women and children even if they do not include female or child subjects, Ruth Faden argues against the approach of Ryan White by saying that excluding women and children from research leads to a decrease in knowledge of the effects of the virus on women, which could result in their decreased health status and earlier death (Faden et al. 1996).

As I will discuss in Chapter 5, the ambiguities present in the Ryan White CARE Act are unacceptable. Adequate funding for research on women with HIV disease must be provided, and research must be done that acknowledges the role of women as mothers but also focuses on other aspects of women's sexual, medical, and social lives. The studies should be inclusive of women of different race/ethnicities, class backgrounds, and geographic areas. The funding of studies for women with HIV who are pregnant and/or who use drugs is also needed. Until the manifestation of HIV disease in women's bodies is better understood, we can expect that this disease will continue to hold devastating consequences for women.

III. Criminalizing Pregnant Bodies

In addition to addressing women only in their role as mothers and stereotyping them as a threat to their partners and children, the Ryan White CARE Act also works to criminalize women with HIV disease. While the language of criminalization present in Ryan White attempts to be gender neutral, the law is insufficient because it does not adequately address gendered issues of transmission and criminalization. Using a framework of feminist analysis and current/past criminal cases involving HIV disease, this section will

clarify how Ryan White's gender neutral policy on criminalization is inadequate because criminalization of HIV disease is different for men and women, and especially pregnant women.

In the middle of Title III, a subsection called "Requirement of State Law Protection Against Intentional Transmission" appears. A few sections earlier, the law stipulates conditions under which grants can be made to individual states for outpatient intervention services. Such services include counseling people with respect to HIV disease and testing them for the presence of the disease in their blood as well as the progression of the disease in their immune system (Ryan White 1990, 24). In the subsection about using state laws to protect citizens against intentional transmission of HIV, the law stipulates that grants for outpatient intervention services cannot be made unless the state has adequate legislation to prosecute individuals who intentionally try to spread the disease to other members of the population. The law then outlines the practices that could be grounds for prosecution, including donating blood, breast milk, or semen "with the purpose of exposing another person to HIV disease"; using a hypodermic needle and providing it to another person with the purpose of spreading the disease; and finally, engaging in sexual activity if the individual is aware of his/her infection and intends to expose another to the disease (Ryan White 1990, 29).

Although the legal stipulations against intentional transmission of HIV disease are arguably necessary for the protection of other members of society, women can face a greater risk of being accused of transmitting the disease when they become pregnant or wish to become pregnant. The criminalization of pregnant women did not come about as a result of HIV disease: as Rachel Roth reports, pregnant women have often found

themselves at the mercy of physicians, other healthcare providers, and, occasionally, local and federal judges in regards to the rights they have to their own bodies (Roth 2000, 95). Within both feminist and legal discourse on HIV, debates about pregnant women with HIV disease often turn into circular arguments over whether the rights of the pregnant woman or the rights of the fetus are more important. More recently, feminist legal theorists such as Jennifer Sinton have been calling for a truce between the constant struggle of “woman v. fetus” that is present in the ongoing discourse of legal human rights, and her argument is applicable to Ryan White. Sinton says,

Rights discourses focus the public’s attention on abstract notions and rhetoric and construct opposition between women and their children. Conferring a right becomes an end in itself. Rhetoric creates the impression that [issues] will be solved once we determine whose rights are more important (Sinton 1997, 195).

Sinton argues that pregnant women will not be protected against the criminal transmission of HIV so long as women are placed in opposition to their children.

Feminist legal theory about HIV provides an appropriate framework of analysis to understand how the risk of criminalization for the transmission of HIV disease can be specific to women, and it can also help clarify some of the dangers in the Ryan White CARE Act. While some legal theorists have chosen to focus on the mother v. child rights battle, others, such as Mary Anne Bobinski, focus on the consequences of this dichotomy for pregnant women with HIV. Bobinski argues that the problem with criminalizing the spread of HIV is that the methods of transmission and the level of risk for transmission associated with each are gender specific. The law does not recognize these gender differences and thus can discriminate against women with HIV. Bobinski argues,

The problem of HIV transmission must be examined to establish whether any unique biological properties based on gender exist. If such biological properties are present,

it is necessary to determine whether and how these differences are reflected in the legal regulation of HIV infection (Bobinski 1994, 8).

Ryan White is unfair to women with HIV disease because it does not take into account the different ways that HIV can be transmitted; the law ambiguously considers only modes of transmission that are universal to both genders. However, when differences in transmission are ignored, women are the ones who pay the price.

Bobinski argues that the language of laws like Ryan White, although they are meant to speak to men and women as equal participants in the spreading and transmission of HIV disease, do not correctly approach issues of criminalization. In their attempts to be gender neutral, the laws are actually more unfair to women. She holds,

Although almost all criminal laws are facially gender-neutral, [as Ryan White appears to be], these facially neutral rules can have both a negative and a disparate impact on women. The negative and disparate impact may be created either in the actual application of facially neutral schemes or by the identical treatment of what are, in fact, different risks (Bobinski 1994, 12).

Although laws of criminalization may on the surface seem to be broad in terms of their unique application to men and women, Bobinski argues that this is simply not the case.

One example of a court case regarding the criminal transmission of HIV which has concerned feminist legal theorists is the Supreme Court's ruling on *Gonzales v. Carhart*, a case which upheld the Partial Birth Abortion Ban Act of 2003. Author Margo Kaplan discusses the ramifications of *Gonzales*, warning that the decision of the case could later be interpreted to prosecute women who transmit HIV to their children (Kaplan 2008). The decision could also be used to criminalize pregnant women with HIV who do not comply with treatments to protect the life of the fetus. Thus, Bobinski's (1994) gendered critique of facially neutral laws could later be used against women because they do not consider the gendered aspects of transmission and criminalization.

Although Ryan White could allow women more autonomy in making medical decisions for themselves and their children, the gender neutral approach used within the law does not take into account the interrelated risks of transmission (and thus criminalization) that are specific to men and women. Many feminist theorists have commented on the fact that pregnant women who do not make medical decisions that favor the fetus they carry, even if such a decision puts their own health in jeopardy, are often viewed as incapable of making good decisions or are stereotyped as bad mothers. Rachel Roth argues, “When doctors and judges [interpret] women’s actions as compromising their commitment to motherhood and the health of their future child, they [come] to see women as irrational, incompetent, and bad” (Roth 2000, 97). In the same way, Ryan White and other state-based legislation could potentially be used against women. Ryan White’s gender neutral, ambiguous language leaves open for interpretation the myriad of ways in which women (read: irresponsible, unfit mothers) can “selfishly” transmit HIV disease to their innocent children.

IV. HIV and Drug Users: The Intersectional Implications of Invisibility

Conveniently, Ryan White makes over \$2.1 billion dollars available for the medical needs of people with HIV disease; however, the legislation offers little to IV drug users with HIV disease. Ryan White can often disserve women with HIV because it does not allow money to be used for the distribution of clean needles, and the bill actually closes on this grave note. In the last lines of Title IV, the law reads, “None of the funds made available under this Act, or an amendment made by this Act, shall be used to provide individuals hypodermic needles or syringes so that such individuals may use illegal drugs” (Ryan

White 1990, 54). Because issues of race, sexuality, and social position complicate the relationship between drug use and HIV, especially for women, an intersectional analysis of the relationship and its reflection in Ryan White should be carefully formed. I explore the gendered, racialized, sexualized, and classed effects of IV drug use and the way in which Ryan White addresses these relationships in an effort to show how the legislation disserves women with HIV.

In 2006, the Centers for Disease Control reported that although drug use is a significant mode of transmission for men and women, the percentage of total women who contracted HIV from the use of IV drugs was much higher than the same percentage for men (HIV/AIDS Fact Sheet, 2006). In 2009, the Centers for Disease Control estimated that approximately 10,000 women in the United States became infected with HIV disease. Of those 10,000, about 15% became infected via direct contact with IV drugs, (but this could be as high as 19%), and a little less than 85% became infected from heterosexual contact (“Basic Statistics” 2009). However, these statistics do not account for the women who acquired HIV by sleeping with a man who acquired HIV through intravenous drug use. The lack of funds for the provision of clean needles can disproportionately affect women, because not only is the percentage of IV drug use transmissions higher for women than for men, but women can also acquire HIV from having unprotected sex with a man who has used IV drugs.

The relationship between sex, race/ethnicity, and drugs also plays a significant role in a woman’s chances of acquiring HIV. In 2011, over twenty five percent of the new cases of HIV in the United States were among women, and that among those women living with HIV/AIDS, nearly 60 percent were African American and 16 percent were Hispanic

(HIV/AIDS Fact Sheet, 2011). Together, African American and Hispanic women only make up approximately 25 percent of the total female population in the United States (HIV/AIDS Fact Sheet, 2003). In 2008, African American women were over 15 times more likely than white women to contract HIV disease at some point in their lives (Harris 2008). The most common way for an American woman to become infected with HIV disease, apart from direct heterosexual contact, is to inject intravenous drugs or sleep with a man who injects intravenous drugs. In 2003, the CDC estimated that about 20 percent of all of the new infections among women in the United States were due to direct contact with IV drugs (HIV/AIDS Fact Sheet, 2003). The World Health Organization reports, "Women are much more likely than men to contract HIV from a single act of unprotected sex with an HIV-infected partner (WHO Joint National Programme on HIV/AIDS 2004). Thus, if the woman has sex with a male who contracted HIV through the use of IV drugs, she is much more likely to become infected than if a man were to sleep with a woman who contracted HIV through the use of IV drugs.

Issues of social class further complicate racial disparities in IV drug use and HIV infection. Diane Lewis argues that HIV incidence is higher for African Americans because of the high rates of drug use in poor African American communities. Her research illustrates how the epidemic is socially and culturally situated in certain geographic areas. At the time that Lewis wrote her piece, almost 75 percent of black women with HIV disease became infected through either direct or indirect association with injection drug use, compared to only 57 percent of white women (Lewis 1995, 58). Lewis additionally argues that black men and women are more likely than their white counterparts to be incarcerated for IV drug use and thus have a greater risk of infection (Lewis 1995, 65). The cultural

stigmatization of people who use drugs can often result in legal stigmatization and discrimination. Ryan White illustrates Lewis's argument, because it identifies drug use as a "promiscuous" behavior and further isolates and stereotypes individuals who use drugs. Because IV drug use significantly affects women's chances of contracting HIV, Ryan White disserves women with HIV disease to a greater extent than men. With no money being provided for the distribution of clean needles and little attention being given to drug users in general, Ryan White does not sufficiently meet the needs of women with HIV disease.

In addition to the fact that Ryan White forbids money to be spent on clean needles for drug users, the act further serves to stigmatize persons who use illegal drugs through Title III, called "Early Intervention Services". Here, the law outlines stipulations for counseling and other such intervention services for patients with HIV disease. Ryan White mentions several times that the direct encouragement of sexual activity and/or drug use via counseling is prohibited if using Ryan White funds. Additionally, the law reads,

Counseling programs carried out under this part shall not be designed to promote or encourage, directly, intravenous drug abuse or sexual activity ... [it] shall be designed to reduce exposure to and transmission of HIV disease by providing accurate information; and shall provide information on the health risks of *promiscuous* sexual activity and intravenous drug abuse (Ryan White 1990, 4) [emphasis added].

"Promiscuous" is defined as, "not restricted to one sexual partner; casual, irregular" (Merriam Webster Online 2012). So if "promiscuous" sex or drug abuse is, by definition, "irregular", a polarity of normal and abnormal behavior is created. If "regular, normal" (read: heterosexual) people engage in sex practices, they are not seen as being at risk. And of course, the healthy (read: "heterosexual") population is assumed not to use IV drugs. When nonheteronormative sex or drug use is considered "promiscuous" or "irregular" behavior, it is easy to transition from "irregular" to "deviant". Given the idea that

“promiscuous” sex and drug “abuse” (note “abuse” and not “use”) is casual or irregular, and the idea of “abuse” is associated with deviance and promiscuity, IV drug users are not viewed in a positive light by Ryan White. Drug use is already stereotyped as deviant in mainstream society, but instead of addressing the stereotype of drug users, Ryan White only furthers this problem.

Feminists have commented on the way that the law reflects the social stigma placed on IV drug users, and especially women and pregnant women who use IV drugs. Paul Farmer elaborates the complexity of sexual activity and drug use, saying that this relationship is often more complicated for women (Farmer et al. 1996). Women who engage in sex work for the purpose of having greater access to IV drugs have a higher risk of contracting HIV disease. In order to combat this phenomenon, Farmer suggests that access to treatment for women struggling with substance abuse must be expanded (Farmer et al. 1996). Feminist authors Rachel Roth, Beth Schneider, and Nancy Stoller also comment on the lack of drug treatment assistance for women, especially women who are pregnant. They argue that instead of seeing pregnant women as in need of medical therapy for their substance abuse problems, they are instead seen as a liability because of the fetus they carry. The authors show that there are few drug treatment centers for women, but even fewer who will accept pregnant women (Roth 2000; Schneider and Stoller 1995). Joe Rhatigan, a co-author in Farmer’s book, comments,

Most often, women IDUs are single mothers who are forced to prostitute, sell drugs, or run shooting galleries to support their habits. They suffer severe discrimination both inside and outside of the drug subculture. What they need is not merely education, but a way out of circumstances in which they necessarily subject themselves to HIV risk (Rhatigan et al. 1996, 231).

Ryan White is insufficient for women with HIV disease who use drugs, because not only does it not address the gendered, racialized, sexualized, and classed problems associated with drug use, but it also does not provide funds for people who use drugs to access clean needles, which would help to prevent the spread of HIV. Ryan White also does not help women have access to treatment for their substance use issues, so even if these women want to alter their use of drugs, it is more difficult and sometimes impossible for them to do so.

V. “Acting Against AIDS” in the Ryan White Treatment Extension Act of 2009: Individual Responsibility and the Vulnerable Subject

In April of 2009, President Obama, along with the Centers for Disease Control and the Office of National AIDS Policy (ONAP), began a domestic campaign to prevent HIV in the United States entitled “Act Against AIDS”. The campaign most closely focuses on gay men, African Americans, and Latinos, groups that currently have the highest prevalence of HIV disease in the United States. According to their website, the next phase of the “Act Against AIDS” advertisements will “focus on reaching specific populations at greatest risk for AIDS, including African Americans, Hispanics/Latinos, and MSM” (“Acting Against AIDS” 2011). The newest campaign encourages people from all over the US to get involved in acting against AIDS by “getting the facts, getting tested, and getting involved” (“Acting Against AIDS” 2011).

While it is appropriate for the government to focus on lowering the prevalence of HIV disease in communities where HIV is hardest hit, the creation and separation of persons into certain epidemiological “risk categories” such as African American, Hispanic/Latino, and MSM does not adequately address the intersectional overlap in such

categories. For example, the studies do not always effectively note the intersection of sexual orientation, race, and risk for HIV disease. Categories of risk separate such groups from the rest of the presumably heteronormative social world, terming them as ‘others’ and leading them to further isolation and stigmatization. Additionally, the campaign’s categories negatively affect members of the population who do not self-identify in an “at risk” category or find themselves specifically termed “at risk” for acquiring HIV disease, because individuals who are not targeted will be less likely to be fully aware of their risk (Dworkin 2005)

Cindy Patton’s skeptical attitude toward epidemiological “risk groups” is still relevant today; Patton notes that categories of risk have had especially detrimental consequences for women. She argues,

AIDS seemed always to be a possession of deviant groups fractured off from the mainstream, and women seemed to be the stitches holding the tattering mainstream together. Capacity to acquire HIV became a signifier of deviance: the slide from ‘risk’ to ‘deviance’ virtually disabled efforts to direct education toward women, or even recognize that women had clinical AIDS (Patton 1994, 99).

In the current Act Against AIDS campaign, women are not mentioned as a specific group “at risk” of HIV, and thus Patton’s words, although penned over fifteen years ago, still have significance today. In the case of Act Against AIDS, women are not seen as a significant risk group, so they are left out altogether as a target population. Thus, when the Treatment Extension Act attempts to target specific groups with HIV, this has special consequences for women, who are currently not being acknowledged by the Act Against Aids campaign as epidemiologically “at risk” for acquiring HIV disease.

In addition, Shari Dworkin and Susan Craddock have argued that the way women are classified within the discourse of HIV provides the basis for heterosexual transmission

while making lesbian transmission of HIV completely invisible. Dworkin calls for better epidemiological surveillance to account for more accurate transmission rates (Dworkin 2005, 619). Susan Craddock also argues that the cultural framing of HIV disease and who is seen as at risk of acquiring the infection can lead to the formation of identities and the production of diseased bodies (Craddock 2000, 159). Both Craddock and Dworkin argue for a more intersectional approach to the study HIV, saying that when risk is categorized and certain groups are targeted for their “risk”, then people cannot fully understand their own chances of contracting HIV (Craddock 2000; Dworkin 2005). Thus, the Treatment Extension Act’s ignorance of the intersectional relationship shared by these categories only further disserves women with HIV in the United States.

Before concluding the discussion of Ryan White, it is important to note the general shift in focus of the Ryan White CARE Act of 1990 and the Ryan White Treatment Extension Act of 2009, because this shift is telling of the consequences of domestic HIV legislation’s deployment of gender. Although little has changed in Ryan White itself in the past twenty years, President Obama’s extension of Ryan White in 2009 created a new initiative to promote individual responsibility and raise awareness about the importance of a person knowing his/her HIV status². The focus of the Extension Act of 2009 is different than the original version of Ryan White, which emphasized the dangers of collectively understood risk behaviors more than individual responsibility³.

² At the end of 2009, the CDC estimated that there were about 56,000 new infections of HIV disease every year in the United States and that about 20 percent of all the people who become infected do not know that they are infected (“Basic Statistics” 2009).

³ In the next chapter, I will show that the Patient Protection and Affordable Care Act of 2010 deploys its own logic of “personal responsibility” as well.

A universal vulnerability approach would argue that the legal language of personal responsibility in Ryan White is detrimental to women with HIV disease because it does not acknowledge the socio-structural inequalities that inhibit some women from 'taking control' of their health. If the state requires all citizens to be personally responsible for their HIV status, then the state should also regulate the distribution of healthcare in such a way that all citizens have equal access to protections from HIV disease. However, Fineman says that the legal language of personal responsibility is often used to justify the state's lack of involvement in the regulation of healthcare. Fineman argues, "Profound inequalities are tolerated – even justified – by reference to individual responsibility and the workings of an asserted meritocracy within a free market" (Fineman 2010, 251). Fineman holds that because the state does not equally equip all citizens with the ability to access healthcare for HIV infection, Ryan White's emphasis on personal responsibility will only allow further health inequality and will not help people who are at risk of HIV disease to take 'personal responsibility' for themselves (Fineman 2008; Fineman 2010).

The Act Against AIDS campaign and the overall attitude of the Treatment Extension Act of 2009 does not take into account Fineman's argument against policies that promote personal responsibility, and inequality is permitted as a result. Like Fineman, feminist HIV theorists, too, have argued that while individuals are responsible for knowing their HIV status, the language of personal responsibility does little to assist persons with HIV disease because it does not take into consideration socio-cultural factors that affect a person's risk (Patton 1994; Farmer et al. 1996; Dworkin 2005). The Treatment Extension Act could do more to ensure that all citizens in the United States had equal access to testing and treatment for HIV disease, but the neoliberal legal rhetoric of personal responsibility

education prohibits the state from taking a role in ensuring that citizens can access the care they need.

VI. Conclusion

In this chapter, I have used an intersectional analysis to illustrate the ways in which the Ryan White CARE Act of 1990 and the Ryan White Treatment Extension Act of 2009 both serve and disserve women with HIV disease. Both of these pieces of legislation deploy traditional gender norms and assume that society operates as a heteronormative unit wherein all individuals have an equal opportunity and/or risk of acquiring HIV disease. Through the grouping of “women, children and families with HIV disease”, a woman is seen as the passive object of the law when compared to the male subject, and she becomes tied to her role as mother.

Furthermore, the gender neutral language of Ryan White allows for women to face a greater risk of being criminalized for the transmission of HIV disease; the legislation does not take into account the fact that the modes of transmission for men and women are both different from each other and interrelated, and many feminist legal theorists fear that it could one day be used against pregnant women for transmitting HIV disease to a fetus or for refusing ARVs or other medical procedures during pregnancy. Women who use IV drugs are often doubly disadvantaged, as first they have HIV and also their health has been jeopardized by substance abuse. The need for more women’s treatment programs and clean needle banks is clear, but Ryan White turns a deaf ear to these women, further marginalizing them from the rest of the presumably ‘healthy’ community.

Finally, the Treatment Extension Act of 2009 gives a great deal of money to new programs which focus on individual responsibility for health; these programs ignore the social, structural, and cultural inequality faced by some groups and assume that men and women share an equal social status. The Act Against AIDS campaign has detrimental effects for women, who are either tied to their role as mothers or are completely invisible in HIV discourse altogether. In the next chapter, I will incorporate the same intersectional and interdisciplinary feminist analysis to critique how the Patient Protection and Affordable Care Act of 2010 is also disserving women with HIV disease. Many of the attitudes and problematic areas of Ryan White are also present in the ACA.

CHAPTER 4: THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

I. Introduction to the Affordable Care Act: Ignoring HIV

The Affordable Care Act has been praised by feminists for introducing 32 million more people into the system of American healthcare (Pearson 2012). However, the law's open arms for the marginalized come at a high price for women. Unlike the Ryan White CARE Act, which deals exclusively with patients who have HIV, the ACA is a more general piece of healthcare reform whose policies should help HIV patients to have better, more affordable access to healthcare. Yet the ACA demonstrates many of the same problems feminist theorists have been critiquing for years, such as the construction of women as 'other' and the legal visibility of women only in a reproductive capacity. The ACA provides better access to insurance by forcing women to stick to traditional, maternal roles; its policies leave little room for women's sexual agency and freedom. The feminist theories analyzed and reviewed in Chapter 2 can help illuminate the ways in which the law's

supposedly progressive policies and provisions deploy gender norms so as to rank women's health needs as a lower priority. Furthermore, bringing feminist legal vulnerability theory into the analysis also highlights new problems with the ACA that require attention; namely, how the ACA uses a traditional and highly gendered account of vulnerability, which only leads to further stigmatization and isolation of women with HIV disease.

Within the ten titles of the ACA, the terms "HIV" and "AIDS" are only specifically mentioned in three sections. Although HIV currently affects over 40 million Americans, including those with HIV and their families, with a new infection occurring in the United States every nine and a half minutes ("Acting Against AIDS" 2011), the disease is only mentioned three times in the 1,024 pages of the ACA! The marginalization of HIV from the ACA is reflective of mainstream society's overall attitude that HIV is no longer a problem in the United States, at least not for people who 'behave appropriately'. The ACA's general marginalization of HIV within healthcare reform treats the over 1 million Americans who are currently infected with HIV disease as though they are unimportant. Because people with HIV are hardly recognized by the ACA, the law will not be able to adequately address their needs.

Moreover, when "HIV/AIDS" is addressed by the ACA, it is a term used to distinguish a group or "population" of people who need special care or attention; the ACA mentions HIV in a long list of other "vulnerable" populations. Also noting the presence of persons with HIV in passing may seem harmless, feminist theory on HIV, feminist legal theory, and universal vulnerability theory can help to demonstrate the ways in which the traditional legal meaning of vulnerability is used against women with HIV disease.

II. The Affordable Care Act's Gendered Construction of Vulnerability: Detrimental Consequences for Women with HIV Disease

The ACA's use of the term 'vulnerable' to describe populations who face an increased risk of contracting HIV disease has several dangerous consequences for women with HIV and thus should be avoided at all costs⁴. The first area of the ACA that mentions HIV disease is found in a subsection of Title II called "Medicaid and CHIP Enrollment Simplification", which discusses the ways in which states will assist individuals in applying for state health insurance exchanges and the Children's Health Insurance Program (CHIP). The goal of this part of the ACA is to simplify the process of accessing healthcare insurance so that more people who qualify for Medicaid or CHIP will be enrolled in these programs. The subsection corresponds with the ACA's more general goal of expanding access to health insurance to all Americans. It states that any person who does not qualify for Medicaid will automatically be screened and enrolled in the National Insurance Exchange, which sells insurance at a discounted price. In the midst of all of this information, the term "HIV/AIDS" appears at the end of a long list of different "populations" of individuals whom this Title seeks to specifically assist. The law reads,

A State shall establish procedures for – (F) conducting outreach to and enrolling vulnerable and underserved populations eligible for medical assistance under this title ... including homeless youth, pregnant women, racial and ethnic minorities, rural populations ... and individuals with HIV/AIDS (Affordable Care Act 2010, 172).

⁴ By terming certain populations as 'vulnerable' to HIV disease, the ACA is using vulnerability in a specific way. As was previously discussed in Chapter 2, the traditional meaning of the word 'vulnerable' is "capable of or susceptible to being hurt or wounded" (Merriam Webster Online 2012).

Although HIV disease is listed in this section along with several other debilitating conditions, its categorization as a vulnerable condition says a great deal about the people who have HIV disease and can have especially harsh consequences for women.

A similar reference to “vulnerable populations” of Americans with HIV/AIDS is made in Title V’s Subtitle D, called “Enhancing Health Care Workforce Education and Training”. This section gives power to the Secretary of Health to award grants to hospitals, medical schools, non-profit organizations, and other domestic healthcare providers to improve the medical services offered to patients. One specific part of the subtitle specifies that the Secretary can make grants to accredited medical schools “to establish, maintain, or improve [training] in the care of vulnerable populations such as children, older adults, homeless individuals, ... individuals with HIV/AIDS, and individuals with disabilities” (Affordable Care Act 2010, 616-617). Furthermore, the law states that priority for grants and other contracts will be given to physicians who wish to “conduct teaching programs targeting vulnerable populations such as older adults, homeless individuals, victims with abuse or trauma, individuals with disabilities, and individuals with HIV/AIDS” (Affordable Care Act 2010, 620).

Placing “individuals with HIV/AIDS” in a long list of “vulnerable populations” may seem rather insignificant; however, the grouping together of these individuals based on their seropositivity for HIV says a great deal about who they are, what they need, and how they are perceived by mainstream society. Feminist theorists such as Robin Gorna and Susan Craddock have argued that the vulnerability paradigm is layered with gendered meaning that becomes attached to a person’s identity. As it is present in the ACA, labeling certain groups as vulnerable to HIV disease is detrimental to women because it constructs

women as victims, essentializes the gendered characteristics of vulnerability, and inaccurately reflects women's risk for HIV

The ACA's use of the vulnerability paradigm to describe people with HIV/AIDS is especially harmful to women because it can construct women as victims of the infection. In addition, the ACA's use of vulnerability robs women of their sexual agency by creating dichotomies of female sexuality. According to traditional gender norms and beliefs about female sexuality, women are not supposed to enjoy sex; thus, women who overtly display their sexuality or who engage in sexual activity as a means of personal enjoyment are often considered to be sexually deviant by mainstream society. On the other hand, a woman who follows the stereotypical norms of female sexuality is seen as an innocent victim of a horrible disease over which she has no control (Gorna 1996). Thus, when people with HIV are labeled by the ACA as a vulnerable population, this renders women either passive, innocent victims or guilty whores. Shari Dworkin also argues that labeling women as vulnerable robs women of their sexual agency. Under the ACA's label of 'vulnerability', women with HIV are seen as unable to control their sexual lives and are presumed to always want to practice safe sex. The idea of 'woman as innocent victim' does not work if the infected woman does not fill traditional gender roles and is perceived to be sexually promiscuous, and thus the law's language of vulnerability creates women who are either innocent victims with no sexual agency or women who are guilty and promiscuous (Dworkin 2005).

A more intersectional and post-structural feminist approach to HIV would argue that the vulnerability paradigm is socially constructed and is therefore dangerous because the characteristics associated with it can become essential to a woman's identity. Through

the gendered meaning of vulnerability, women are seen as being more vulnerable to HIV because they are presumed to be 'weaker' and more passive than men. The characteristics of vulnerability become feminized so that to be a woman means to be always already vulnerable to HIV infection. The criteria for being labeled 'vulnerable' to HIV disease becomes an absolute identity, such that if a person self-identifies as a certain ethnic, social, or sexual identity, he/she is automatically considered "vulnerable." For example, women of a certain racial/ethnic minority are often automatically seen as being 'at risk' for HIV. Oppressions that result from the power structures associated with women's identities are masked by assumptions that certain characteristics, such as passivity or even femininity itself, are essential to vulnerability (Craddock 2000, 160).

Following the gendered logic of vulnerability in the ACA, Dworkin argues that because men are expected to be masculine, hypersexual, and sexually impulsive, their 'vulnerability' to HIV disease is not accurately portrayed. She states,

Men are conceived as so masculine as to not take into account their partner's needs and are unwilling to control their sexual power/desire ... In reality, men are vulnerable to HIV just as women are, through male prostitution, rape, and population migration; but these facts are not taken into account when assessing a man's risk for HIV (Dworkin 2005, 617).

The ACA's use of vulnerability to describe people with HIV is dangerous for women because it is traditionally gendered; when masculine and feminine traits become attached to vulnerability, both men and women cannot accurately understand their risk for infection (Dworkin 2005; Higgins et al 2010; Aggleton 2004).

The conversations of Gorna, Dworkin, and Craddock are useful when attempting to understand the dangerous consequences of the ACA's use of vulnerability. In addition, feminist legal vulnerability theory about HIV could be introduced to this analysis to

produce a more interdisciplinary framework of the ACA's deployment of traditional vulnerability and the consequences this holds for men and women. Like Gorna, Dworkin, and Craddock, Martha Fineman argues against the law's use of the vulnerability paradigm and instead advocates for a redefinition of vulnerability that is free from the gendered assumptions of identity. While the ACA understands vulnerability to be a condition of risk, Fineman holds that vulnerability should not be an identity category into which one is placed because he/she is of a certain age, race, or sexual orientation. Instead, Fineman sees vulnerability theory as a way of bringing further legal equality for those infected with HIV disease (Fineman 2008).

Fineman's theory of vulnerability is very useful in strengthening arguments against the vulnerability paradigm in the ACA that Gorna, Dworkin, and Craddock have so carefully crafted. Vulnerability theory helps dissolve the ACA's gendered logic of traditional vulnerability because it places all people on the same, universally vulnerable level. If vulnerability becomes universally and legally recognized, women who are considered always already vulnerable to acquiring HIV disease will not be stigmatized as 'weak' or 'passive', because everyone will be considered vulnerable.

III. Personal Responsibility Education: Helping 'Vulnerable' Women with HIV to Avoid Pregnancy

The ACA uses a traditional language of vulnerability throughout its 1,024 pages in order to designate certain groups that need special attention. In addition to being briefly mentioned in Titles II and V, HIV disease is mentioned a third time in Title II, which discusses maternal health and the care of children. Section 513, beneath Subtitle L, is entitled "Personal Responsibility Education". This section of the ACA allots states at least

\$250,000 each for fiscal years 2010 - 2014 to use towards “personal responsibility education”. According to the law, states must collect data from the Centers for Disease Control and Prevention National Center regarding the state pregnancy rates of youth between the ages of 10-14 and 15-19. This data is to be analyzed for trends and other statistically significant increases/decreases in pregnancy and birth rates in youth between these ages. From there, the state must make goals to reduce the pregnancy and birth rate numbers and think of creative ways to use the grant money in order to reach youth. The law reads,

The secretary may require (III) a description of the State’s plan for using the State allotments provided under this section to achieve such goals, especially among youth populations that are at the most high-risk or vulnerable for pregnancies or otherwise have special circumstances, including youth in foster care, homeless youth, youth with HIV/AIDS, and mothers who are under 21 years of age (Affordable Care Act 2010, 347-348).

Furthermore, the term “personal responsibility education” has been defined as “a program that is designed to educate adolescents on both abstinence and contraception for the prevention of pregnancy and sexually transmitted infections, including HIV/AIDS” (Affordable Care Act 2010, 349). The more detailed and innovative a state’s plan to enact such personal responsibility education, the more money will be designated for the use of that state.

The ACA’s discussion of young, pregnant women is particularly appalling in this section, and I argue that the ACA’s depiction of young, pregnant women works to render women invisible in HIV law and to label women as a public health threat and blame them for the spread of HIV disease. Much like the other areas of both Ryan White and the ACA, feminist theory can help to deconstruct the way the law is disserving women through its traditional use of gender. One of the many consequences of young women with HIV disease

being portrayed as vulnerable to pregnancy is that women who are not mothers become totally invisible in HIV discourse. Here, the ACA excludes 'women' as a broad category of people and only acknowledges young, HIV positive women so as to 'protect' them from pregnancies. Patton argues that a legal emphasis on women as mothers only has been traditionally used to link the "gay, queer disease" to the rest of the "heterosexual public" (Patton 1994). Patton's comments are certainly relevant to the Affordable Care Act, which is essentially targeting young, HIV positive women as 'in need' of education so that they will know better than to get pregnant. Through the language of personal responsibility, the ACA stigmatizes pregnant women with HIV, blames them for transmitting HIV to the 'innocent' heterosexual public, and renders other women who are not pregnant unimportant to HIV law.

In addition to women's general visibility in HIV discourse, this section of the ACA can also be used to transform women's bodies into a threat to public health. Robin Gorna's work can be used to illustrate that the language of the ACA is very degrading to HIV positive young women because it stereotypes them as vectors of the disease. In her work, Gorna discusses different "stereotypes of contagion", meaning people or practices which are stereotypically associated with HIV (i.e. "vulnerable" populations and specific sexual behaviors). Gorna states, "[The] stereotypes of contagion create fantasies of dangerous concentrations of HIV. Women are imagined as fearful reservoirs of infection – static pools of festering fluid that may be foisted on an unsuspecting public" (Gorna 1996, 74). Often, a woman with HIV is no longer seen as a person with rights and human liberties, but rather she becomes a physical manifestation of the virus itself; she loses her identity as a woman and becomes a woman with HIV, which turns her into a diseased body. Through the

language of the ACA she is thus seen as a threat to public health. Tamsin Wilton adds to Gorna's analysis, arguing, "AIDS discourse generally constructs a familiar model of woman-as-risk-to-man, both sexually and maternally. Prostitutes in particular, and women generally, are described as 'reservoirs of infection' or as 'an index to the spread of heterosexual AIDS' (Wilton 1997, 69).

As in the Ryan White Treatment Extension Act of 2009, the ACA also invokes the language of "personal responsibility". The words "personal responsibility" are reflective of the neoliberal subject, implying that a person's decisions and choices are his/her own responsibility (Simien 2007). So if a young woman who has little family support and/or who has no access to higher education or even the opportunity to finish high school becomes pregnant with the child of a man who is giving her money to sleep with him, this pregnancy is her "responsibility" (read: 'problem'). If all citizens are supposed to be "personally responsible" for their own actions, the state gets a free pass to ignore the needs of people whose lives they deem as unacceptable or wrong. Returning to the example of the young woman mentioned before, if it is this woman's "personal responsibility" to make sure that she does not become pregnant, it is her fault if she does become pregnant. It is also her fault if, as a result of that pregnancy, she is cast further into the abyss of poverty and social stigma. Thus, women with HIV disease who are unable to meet the neoliberal expectations of self-sufficiency are often blamed for their own failures and cannot access the help they need.

Furthermore, notice that "personal responsibility education" for young men with HIV disease is never mentioned. In spite of the lack of a female-controlled HIV prevention method, the ACA's words on "personal responsibility education" do not even address men,

who are every bit as likely to spread HIV through the use of a “diseased penis” as a woman with an “infected vagina”. However, the very idea of a penis being described as “infected” or “diseased” seems ridiculous. Gorna’s description of the vagina as a “fearful reservoir of infection,” and a “static pool of festering fluid that may be foisted on an unsuspecting public” (Gorna 1996, 74) would never be used to describe a penis, which is traditionally viewed in American society as the symbol of male virility. It is as if all responsibility for the transmission of HIV is removed from the penis, allowing the full weight of “personal responsibility” to bear on the infected vagina/uterus, depending on who it is infecting, of course. The state is throwing money at “vulnerable” women to ensure that they stay out of trouble and do not become pregnant, and thus it seems the law is trying to protect women from *themselves* by keeping them away from the rest of the healthy population. The law regards women as the problem, wanting to keep them from reproducing rather than to keep them from being exploited and subjected to poverty through an unwanted pregnancy.

Not only does the law acknowledge women as the sole transmitters of HIV disease by not acknowledging men’s ‘need’ for ‘personal responsibility education’, it further states that abstinence is the best method of prevention, followed by contraception (i.e. condom use). The law is essentially saying that the best way to stop the diseased vagina (read “woman”) from infecting a man, or god forbid a helpless child, is to make it altogether inutile. When a woman becomes infected with HIV, she becomes transformed into a diseased body and is marked as “vulnerable” and “at high risk” for pregnancy by the law, which is giving away thousands of dollars every year to keep her from getting pregnant! If a woman must use her infected vagina for sex, which Gorna argues causes her to be seen as a licentious whore, then the next most important thing to do is to protect the *male* with

whom she is having sex. Nevermind the fact that there is currently no effective way for women to protect themselves from the infected *penises* of their husbands, partners, boyfriends, lovers, and clients. Gorna notes, "In the absence of an effective microbicide or other woman-controlled technology, there is nothing a woman herself can do to reduce her risk of acquiring HIV" (Gorna 1996, 25). According to the ACA, women are being expected to take "personal responsibility" for themselves when there is not even an effective method of HIV prevention over which they have control! The ACA is charging women with a job that they have not been fully equipped to perform and is then blaming them when they fail.

While using feminist theory to do a gendered assessment of the ACA, a feminist vulnerability perspective would further assist in this critique by presenting an alternative solution to the neoliberal language of personal responsibility education, which the ACA heavily promotes. Martha Fineman's work on vulnerability achieves a better legal framework through which HIV disease can be regulated by rejecting vulnerable populations and identities altogether. Fineman discusses the problem with traditional vulnerability as it is used in the ACA, saying,

Vulnerability is typically associated with victimhood, deprivation, dependency, or pathology. For example, public health discourse refers to "vulnerable populations," such as those who are infected with HIV/AIDS ... In contrast, I want to claim "vulnerable" for its potential in describing a universal, inevitable, enduring aspect of the human condition that must be at the heart of our concept of social and state responsibility (Fineman 2008, 8-9).

Fineman's argument shows that the ACA is riddled with areas where 'personal responsibility' is heavily promoted as a way for the state to evade its responsibility of regulating the care of its citizens and their access to social goods.

If a vulnerable subject were addressed by HIV law, the state could play a larger role in ensuring that all people with HIV disease had access to medical care. Fineman states,

“Profound inequalities are tolerated – even justified – by reference to individual responsibility and the workings of an asserted meritocracy within a free market” (Fineman 2010, 251). However, the vulnerable subject would replace the neoliberal subject in the law, which would make the law’s marginalization of women with HIV disease much less tolerable. In addition, implementing a vulnerable subject would be more inclusive of all women with HIV, not just women with HIV who are pregnant, by acknowledging all citizens as equal through their universal, vulnerable status.

IV. Conclusion

After reviewing the problematic ways in which the Affordable Care Act depicts women with HIV disease, it is clear that a feminist critique helps in assessing the consequences of the law’s traditional deployment of gender for women. However, I argue that an interdisciplinary and intersectional analysis which includes vulnerability will further the conversation by allowing for a solution to the labeling of women as vulnerable and the rhetoric of personal responsibility education. By using feminist scholarship as well as feminist legal theory to assess the ACA’s use of gender, I have demonstrated that women with HIV disease who are not pregnant are rendered invisible through the law’s use of the vulnerability paradigm. Furthermore, the law views women as a public health threat, holding women, and especially younger women, ‘personally responsible’ for transmitting the disease. By applying feminist legal vulnerability theory to the ACA, it is clear how the transition from the neoliberal subject to the vulnerable subject could help address some of the gendered problems which are engrained into this landmark piece of healthcare reform.

Although debates about the Affordable Care Act continue to rage on before the Supreme Court, people with HIV disease, and especially women with HIV, are still being subjected to discrimination and decreased life chances. Regardless of one's political opinions of the ACA, it is clear that the law's use of the language of vulnerability and its deployment of traditional gender norms and roles is very problematic and holds complicated consequences for men and women with HIV. The ACA aims to protect the healthy population from all of the "sick people" and does not provide sufficient means of treatment and protection for people with HIV disease. Furthermore, it disserves people who have HIV by labeling them as a special, vulnerable group that needs special assistance in order to learn to be "personally responsible" for themselves.

CHAPTER 5: A VISION FOR THE FUTURE OF HIV LEGISLATION

I. A Summary of the Interdisciplinary Approach

Through an interdisciplinary and intersectional feminist analysis of the Ryan White CARE Act, the Treatment Extension Act, and the Affordable Care Act, I have shown the consequences of this legislation's problematic use of gender for women with HIV. I have argued that the traditional way in which gender is deployed in HIV discourse is harmful to everyone with the disease, but it can have especially harmful consequences for women. From the traditional legal use of vulnerability and the labeling of women with HIV as 'other' to the neoliberal subject and the logic of personal responsibility education, I have illustrated how the law's use of traditional gender norms and expectations can disserve women with HIV. Although this current HIV legislation does not treat women as equal subjects and assigns them an inferior status, the law could be rewritten in order to better

address and respond to the domestic epidemic using Fineman's theory of universal vulnerability.

In this final chapter, I advocate for a feminist legal approach to HIV that asserts a vulnerable subject instead of a neoliberal, masculine subject. The application of the universal vulnerability thesis to HIV legislation would result in a better legal approach to domestic HIV, because it would assign all individuals a universal human status while decreasing the stigma of vulnerability to HIV and increasing the state's role in regulating healthcare services. The universal vulnerability thesis cannot simply be added onto Ryan White or the ACA, and thus the current domestic laws governing HIV disease will ultimately need to be replaced. The assertion of the vulnerable subject in the recreation of these laws will better serve women with HIV disease because it speaks to the universal vulnerability of all people.

II. The Responsive State: Improving the Health of Women with HIV

The success of the assertion of a vulnerable subject in HIV law is contingent upon the state's response of assuming a greater role in the regulation of social goods such as healthcare. The purpose of acknowledging universal vulnerability is so that the state can better address socio-structural inequality. The application of the vulnerability thesis to HIV law would allow the state to assume a greater role in ensuring that women with HIV disease have access to quality healthcare services, such as experienced physicians, affordable prenatal care, and HAART. Ideally, the state would respond to its vulnerable citizens by creating new HIV legislation that better addresses the domestic epidemic and responds to the needs and experiences of women. This would require The Ryan White

CARE Act and the Patient Protection and Affordable Care Act to be discarded and rewritten based on a vulnerable subject.

A universal vulnerability approach to healthcare in the United States would improve the lives and overall health of women with HIV disease in three main ways. First, an HIV law based on vulnerability theory would recognize the different social positions of citizens, resulting in the regulation and more equal distribution of social goods. Secondly, a universal vulnerability law would create equality through the eradication of the “sameness of treatment” mentality of equality that is currently present in HIV law. Finally, a new HIV law that asserts a vulnerable subject would de-stigmatize vulnerability to HIV infection by deconstructing the traditional vulnerability paradigm.

Vulnerability to HIV can be the result of a the way in which a person’s social status, health status, age, economic position, or even race/ethnicity allows him/her to access systems of power. Because everyone is positioned differently within society, some citizens currently enjoy more access to the systems of power than others (Fineman 2010). Universal vulnerability theory’s recognition of the different positions of women in society is important because, as Fineman argues, recognizing all human beings as vulnerable does not automatically result in equality. She argues, “While human vulnerability is universal, constant, and complex, it is also particular. While all human beings stand in a position of constant vulnerability, we are individually positioned differently. We have different forms of embodiment” (Fineman 2010, 258). In order for a law that acknowledges universal vulnerability to be successful, the state must step in to regulate the currently unequal distribution of social goods, because some currently enjoy more access to these goods than others.

Through the law's recognition of the different social positions of universally vulnerable citizens, the state would be able to better respond to the institutional practices that create inequality. The new HIV law would specifically assist women with HIV disease, who are more likely to have a lower social status, by providing health and social services that meet their needs of basic housing, childcare, prenatal care, transportation, and general healthcare for their infection. Because Fineman believes that a person's vulnerability to HIV infection is directly related to his/her access to power structures (Fineman 2008, 16), women with HIV disease would be less likely to have access to such services without better legislation that addresses universal vulnerability. When the state takes better care of women with HIV by providing such services, it decreases women's risk of HIV infection, which in turn helps the state save the money otherwise spent on treatment of women with HIV. For example, if the law provided better access to treatment for women who use drugs, then these women would be less likely to contract HIV through the use of a dirty needle and/or less likely to spread the disease if they are infected. The state would also save the money that would be spent treating these women for their HIV infection. A new HIV law that asserts a vulnerable subject would encourage the government to respond to citizens in need, and the state would be dually rewarded by having to spend less money on treatment for people with HIV disease.

In addition to addressing how the different social positions of citizens affect access to power and thus vulnerability to HIV disease, a new HIV law that speaks to a vulnerable subject would move from a "sameness of treatment" mentality of equality to an equality that is more just and inclusive of women. In order to have more equal opportunities in

healthcare for women with HIV disease, the state must do a better job in regulating the power structures that govern who has access to healthcare. Fineman holds,

Achieving some viable mechanisms of equal opportunity and access would demand more from the state in terms of rules and regulations restricting the unfettered autonomy of some, as well as a more just reallocation of some existing benefits and burdens within society (Fineman 2010, 261).

Equal opportunity, rather than “sameness of treatment” would better serve women with HIV disease by redistributing access to healthcare in a more just manner. Instead of some individuals paying top dollar for practically unlimited access to healthcare, a new HIV law based on vulnerability would allow the state to redistribute healthcare access based on need. This would also reduce the burden on women with HIV to pay for the advanced care that their bodies require, and it would allow all women with HIV to access costly treatment they would otherwise be unable to afford.

Finally, HIV law that asserts a vulnerable subject should be implemented in order to decrease the stigma associated with being seen as traditionally vulnerable to HIV disease. In Chapter 4, I discussed how the traditional vulnerability paradigm is feminized so that to be a woman means to be always already at risk of HIV. Fineman argues that to traditionally label a group of people as ‘vulnerable’ to a disease or condition is to assign them a status of deviance, pathology, and stigma. She argues that we must deconstruct this identity, saying,

Public health discourse refers to ‘vulnerable populations’, such as those with HIV/AIDS ... In contrast, I want to claim ‘vulnerable’ for its potential in describing a universal, inevitable, enduring aspect of the human condition that must be at the heart of our concept of social and state responsibility. Vulnerability is thus freed from its limited and negative associations and is a powerful conceptual tool with the potential to define an obligation for the state to ensure a richer and more robust guarantee of equality than is currently afforded under the equal protection model (Fineman 2008, 8-9).

If new HIV law asserted vulnerable subjects, then the stigmatization that accompanies being vulnerable to HIV would be detached from specific identities by showing systems of

power that work together to privilege some people at the expense of others. Universal vulnerability in HIV law would better serve women with HIV by removing some of the stigma associated with being labeled as traditionally vulnerable to the virus. The new law would allow women with HIV disease to feel more comfortable with accessing treatment for their condition and would help them to live longer, healthy lives.

III. Feminist Objections to Fineman's Argument

Although feminist scholars have argued against the use of traditional vulnerability to describe women, not everyone would agree that Fineman's vulnerability thesis is a good solution to the legal invisibility of women with HIV. Some feminists are more skeptical about increasing the state's role in protecting 'vulnerable citizens', arguing that this would actually bring more harm to women than good. Feminist theorist Iris Marion Young argues against the rhetoric of the masculinized protector state, saying that this framework can be dangerous, especially for women. In her article "The Logic of Masculine Protection: Reflections on the Current Security State", she contrasts the idea of the masculine aggressor who violates and abuses women with the ideology of the benevolent, masculine protector who watches over the vulnerable and weak, ensuring that no one harms them (2003). She broadens this framework and then applies it to the state, arguing that President Bush took on the role of the masculine protector after the September 11, 2001, attacks on the World Trade Center and the Pentagon. She argues that Bush used the idea that the United States and its citizens were vulnerable to further attacks by Al Quaeda in order to expand executive power. The idea that Bush was 'protecting' American citizens from the 'bad

masculine oppressors' justified his expansion of judicial power and his declaration of war on Iraq (Young 2003, 3).

Young's argument could easily be applied to the universality of vulnerability; if the citizens of the state are seen as vulnerable, the state is given more power with the expectation that social good will be better regulated. This increase in government power could create a masculine protector state, which would place women with HIV disease at a greater disadvantage. Young shows that women are often disserved when the state is viewed as the masculine protector, saying, "Central to the logic of masculinist protection is the subordinate relation of those in the protected position. In return for male protection, the woman concedes critical distance from decision-making autonomy" (Young 2003, 4). Young would disagree with Fineman's universally vulnerable legal subject by arguing that in order to have protection from the state, protection that is deemed necessary for 'vulnerable citizens', one must sacrifice individual autonomy and freedom. She would also argue that the assertion of universal vulnerability in the law has the potential to give too much power to the state and thus runs the risk of transforming the state into a masculine protector. Young argues against the state's role as masculine protector because under this system, citizens are expected to comply with state demands and can be taken advantage of as a result (Young 2003). Some feminists would certainly argue that applying the vulnerability thesis to healthcare legislation would give the state too much power and put women at further risk of being subordinated to a masculine authority.

In response to Young's assertions, I point out that she is using a traditional definition of vulnerability; for the sake of her argument, Young does not consider vulnerability as universal, but rather sees it as being tied to individual identity. Fineman

calls for a responsive state that “mediates” our vulnerabilities and “advocates” for us on behalf of them (Fineman 2008, 10). In order to do this in a way that fosters equality, the vulnerability approach assigns everyone the same status. Rather than treating some subjects as needing more ‘protection’ from the state than others, Fineman argues, “Vulnerability analysis demands that the state give *equal regard* to the shared vulnerability of all individuals, transcending the old identity categories as a limitation on the recognition that the state has a vital role to play in protecting against discrimination” (Fineman 2008, 20) [emphasis added]. Because both men and women would be considered equal under Fineman’s vulnerability thesis, this would help to protect against the rising of a masculine protector state.

Although there is a possibility for state corruption if the law addresses the vulnerable subject, a better, more equal legislative policy to address HIV is greatly needed and could be achieved through the legal adoption of Fineman’s vulnerability thesis. However, feminists should still apply the theory with caution so that a masculine, autonomous state is not created. Furthermore, a discussion of the way in which identity categories become attached to or associated with different systems of power would also be important for feminist theorists to consider, as this has a significant impact on a person’s vulnerability to HIV disease.

IV. Conclusion

In addition to recognizing socio-structural inequality, revising “sameness of treatment” equality, and decreasing the stigmatization of vulnerability to HIV disease, the

vulnerability thesis would also help the United States meet the overall goal of the National HIV/AIDS Strategy, signed by President Obama in July of 2010. The strategy reads,

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination (National Strategy 2010, 5).

Ending the legal discrimination and stigmatization of people with HIV would help the law to better assist women with the disease. When women and men are seen as equal, vulnerable subjects, the law will be better able to address the gendered differences in risk for and transmission of the disease. Ultimately, the application of Fineman's vulnerability thesis would help address the gender inequality that is currently present as a result of the traditional deployment of gender in current domestic HIV legislation.

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