

**‘The Secret is the Power, not the  
Knowledge’: Reconfiguring the  
Discourse of HIV/AIDS-related Stigma  
in Durham, NC**

A Senior Distinction Thesis

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## Abstract

What are the conditions in which stigma is held to be a common sense factor of HIV/AIDS, yet is mutable in the ways people experience stigma? My research analyzes the terrain in which this question is precipitated, and I will evaluate stigma as a lens for understanding broader questions of politics and care that are embedded with American notions of self-hood. The national history of HIV/AIDS, Goffman's work on stigma, and neoliberal policies, laws, and education measures have converged to create certain imaginations of attribution and individuality for those who live with the disease. People who are HIV-positive are feared, seen as immoral and tainted, and they are blamed for contracting the virus and failing to receive the proper care. The dominant discourse creates feelings of isolation and has led to beliefs that stigma is permanent and universally affects HIV/AIDS patients, so one must remain confidential about a diagnosis for protection from stigma. From policies that move towards privatized healthcare to the rationale that stigma can be localized to a body, these aspects of life rely on ideals of self-help and have precipitated perceptions of HIV/AIDS as solely individual experiences. Instead of seeking ways to confront these perceptions, society ultimately advocates for concealing diagnoses to mitigate stigma. The localization of stigma ignores the social construction of stigma that is informed by history, culture, and power, and in this very context, my participants have demonstrated agency by disclosing their stories. By illuminating social ties through dialogue, they have contested the dominant discourse that they are secluded from the rest due to their mark of stigma. In this ethnography, then, I will explore how stigma functions and is maintained in a space where discursive practices, neoliberalism, and medical intervention intersect.



## Introduction

### Running for a Change

“Would you like some candy and condoms?” The girl holds the brown wicker basket up to my face and looks at me expectantly. Peering in, I see the colorful candies lying oddly yet innocently next to the equally vibrant condoms. The girl is young, wearing a shirt decorated with cat faces, furry angel wings, and a white shiny tutu. This haphazard outfit is just as peculiar as the contents of the basket, perhaps deliberately coinciding with each other to normalize the normally unusual. I obligingly grab a few pieces of candy and begin to process my surroundings.

The day is warm and saturated with sunshine—the perfect day for a run. I am at a 5K race that benefits individuals affected by HIV/AIDS. Racers are sporadically crossing the finish line, and as each person approaches the end, the small crowd waiting by the finish line claps and cheers for encouragement. People of all ages are milling about in the enclosure by the finish. A few by themselves, some with families, and most with friends. Many are wearing red ribbons, and one young man sports a shirt stating “Face Stigma” in bold font. From the harmonious cheers to the ubiquitous red, people at the race seem to have come for the same reason: to publicly announce their support for those with HIV/AIDS.

Although the race attendants appear to be outspoken about their support, the race does not have the high attendance numbers I am expecting. When I initially pulled into the parking lot, I thought I had arrived at the wrong location. I could only see a small sign to confirm the race site, and having arrived an hour after the race began, I was bracing myself for traffic and congestion. From previous experience with a marathon, I was expecting more people to be there to announce the race’s presence. However, I was able to easily park a few feet from the finish line as the 5K turned out to be a modest one. Why was there such a low turnout rate? Was this

due to poor race advertisement? Or are issues regarding HIV/AIDS usually hidden out of sight and out of mind?

As I ponder, I begin to stroll around a cluster of six tables, each advertising the names of HIV/AIDS advocacy organizations. This small health fair is taking place right outside of the finish line, and each table is decorated with posters and covered with brochures about issues related to HIV/AIDS. HIV Test: Think About It. STD Fast Facts for Young Women. 12 Reasons: Let's Talk Before We Have Sex. The brochures come in English and Spanish, and many depict concerned or smiling faces of men and women on the cover. As I approach one table, a woman hands me a brochure entitled "Guess Who's Got It?", telling me that this pamphlet has been especially popular today. I take what she offers, and concurrently, I question whether the brochure has actually been favored today or whether she just wanted me to feel more comfortable in accepting the pamphlet.

I eventually reach a table where a middle-aged woman is sitting and fanning herself with one of the flyers. As I look over the papers at her table, she notices my interest and begins to tell me about an upcoming HIV Treatment meeting. Encouraged by her initiation at conversation, I decide to ask her a more personal question, one that would allow me to get to know her better yet would not be assumptive of her reason for being at the race. After carefully crafting my next move, I smile at her and inquire sensitively, "If you don't mind me asking, how did you initially become involved with the race?"

After a brief moment of hesitation, Irene strongly declares, "Well, I am HIV-positive." Unprompted, she proceeds to recount to me stories of the discrimination she has faced, how HIV has affected her life, and her work with a support group. She continues to talk without regards for time, and I am taken aback by Irene's openness.

Because I had assumed that those who are HIV-positive would be reluctant to talk to a stranger, I am surprised at Irene's open disclosure of her HIV status with my simple question. I had presumed that entry to the HIV/AIDS community would have taken more time due to the sensitive nature of my research topic. At that very moment, I had been waiting for two weeks to hear back from an AIDS organization about conducting fieldwork there. Somehow, I was lucky that day, or so I thought. Through my interviews and observations, I have realized that Irene's open disclosure to me was not due to luck, but her decision to share her status was a sign of agency in the face of stigma.

### **Road to the Research Question**

For most of my life, I have known that HIV/AIDS existed. From school textbooks, I knew that the virus could not be transmitted through casual contact, and someone would have to drink many gallons of saliva from a HIV-infected person to be able to acquire the virus. Moreover, someone cannot technically contract AIDS, as this is the late stage of HIV and happens only when the immune system is too weak to fight off additional infections. I also knew that HIV had become a pandemic from the media, and as a middle school student, I was inspired to find a cure through research even when I had never set foot in a lab. The most detailed information I knew about HIV/AIDS was what I had learned from microbiology last semester: HIV is a retrovirus with a gp120 receptor that first binds to the CCR5 receptor on a macrophage, and then later, invades helper T cells by binding to the cells' CD4 receptors. A mechanical, impassive description of the infection process of the virus. I knew the basics and I knew the terminology, and I knew I was touched by that indiscriminate childhood ambition of saving the world.

But what is knowledge without experience? What I lacked was a grounded understanding of HIV in everyday life. I did not have any friends who were affected by HIV, nor had I considered what it meant to be affected by the disease beyond the cellular level. With the superficial knowledge in my mind, I took on an internship at NO/AIDS Task Force (NATF) in New Orleans. I knew that this particular NGO targeted a health problem that appealed to the science and public health side of my interests, but besides this, I was not aware of how the community had responded to the pandemic or exactly how complex the social and cultural issues related to HIV/AIDS are.

Working at NATF was, to say the least, a learning experience. One day, my supervisor and I began to talk about the history of HIV/AIDS. She confided in me that she believes that HIV/AIDS is still perceived as a gay disease even though African American women are now the most at risk for contracting HIV/AIDS. I had to pause for a moment, surprised that she perceived the stigma surrounding the disease to be unchanged. In the 1980s when HIV/AIDS was new and baffling, the disease did primarily affect the gay community, but thirty years have passed since then. I was having a difficult time wrapping my mind around the idea that HIV/AIDS may still be viewed as a gay disease when our society knows much more about the biological mechanisms of the disease now.

However, I later learned that knowledge may not necessarily be internalized into beliefs. During an outing to a popularly designated “gay bar,” one of my friends found a pocket knife, and another person remarked with a smile, “Don’t take that knife with you. It probably has AIDS on it.” He said it casually, as if it was a joke to him. I thought an educated student would have known better, that someone cannot contract AIDS from an object and that not everyone who is gay is HIV-positive either. Later that night, a separate individual commented on how everyone

probably got AIDS from being at the bar. Another baffling and painfully wrong statement. I had been naïve, my supervisor was right, and I became determined to learn more about HIV/AIDS-related stigma.

After reading about the state of HIV/AIDS, my original research question focused on the characterizations of stigma and how stigma affects people on an individual and societal level. This question dealt with how people live with HIV/AIDS and how others treat them. With each encounter in the field, though, I have noticed that my participants have not necessarily expressed how stigma impacts their self-esteem or perceptions, but rather, the question of disclosure has been a common denominator in our conversations. I had assumed that few people affected by HIV/AIDS would not want to openly share their private diagnoses with me, yet Irene had shown no qualms about telling me, a stranger.

Thus, my research question shifted to how stigma functions and is maintained in a space where discursive practices, neoliberalism, and medical intervention intersect. Evaluating stigma can provide a lens for understanding broader questions of politics and care. By employing stigma as a catalyst for thinking of a greater context, I hope to illuminate the processes that have structured notions of self-hood that pervade American life. In the realm of HIV/AIDS then, I will analyze the common notion that silence about one's diagnosis will act as a protective barrier against stigma, but paradoxically, these secrets appear to hold power in keeping stigma alive. In response to the societal constraints caused by stigmatized perceptions, however, HIV-positive individuals have found ways to navigate the world by speaking out about their status, forming their own identities through the production of speech. By evaluating these dynamics, I hope to illuminate how discourse operates on multiple levels of power in the terrain of HIV/AIDS-related stigma.

## **Methodology**

To answer my questions, I interviewed twelve participants, some who are HIV-positive and others who are affected by HIV/AIDS in other ways through their work or social lives. For example, some participants work in education, another is a lawyer, and yet another works at a nursing school. These people encounter HIV/AIDS in a variety of situations in the community, and I hope these diverse perspectives can inform my research in a more comprehensive way.

My participants were gracious enough to share their stories with me, and I talked to each of them in open-ended interviews for as little as thirty minutes to over four hours. For some, I asked more concrete questions to keep the conversation going, but for others, no set questions were needed as they were comfortable in speaking. I attempted to meet in informal settings such as the participant's house or office to keep the atmosphere casual, and sometimes, my participants would also help me to identify potential participants that I would then contact.

Many of these participants are also members of a support group that I attended for observation. This support group is open to all women, not just those who are HIV-positive. Although I cannot share any confidential information about the women's personal lives due to the nature of a support group, I will discuss the overall dynamics of the group and the general topics that were mentioned. I also conducted observations at meetings such as one that focused on giving an update of HIV treatments, a meeting with a community advisory board, a meeting held at AIDS Alliance, and more. Throughout the process, I collected brochures about HIV/AIDS and medications for analysis, and I will also be drawing on media examples to support my argument.

I hope that through this variety of angles, I can more thoroughly answer my research question to determine how HIV/AIDS-related stigma is maintained, configured, and reconfigured through the convergence of politics and discourse in Durham, North Carolina.

### **Previous Work on HIV/AIDS**

In efforts to respond to the HIV/AIDS pandemic, a group of scientists recently conducted a literature review of studies on HIV/AIDS-related stigma. In this review, the authors found that scientific literature has been dominated by “stigma assessment” studies, which explore “the perceived or enacted stigma experienced by [people living with HIV/AIDS], stigmatizing beliefs held by scientific groups or the general population, or the effects of stigma on access to and utilization of care, prevention, and treatment services.”<sup>1</sup> The authors found that the overwhelming majority of studies have overlooked pre-existing and overlapping stigmas, as well as how stigma can function at the structural or institutional levels, and this oversight further hinders the design of effective stigma reduction interventions.<sup>2</sup> While this review acknowledges that stigma is complex and varies by cultural context, at the same time, the scientists behind the literature review emphasize the need for the standardization of definitions of stigma and measurement techniques to provide more accurate results.<sup>3</sup>

Anthropology is valuable in its ability to address the gap in knowledge that the scientists mention—the ways in which stigma operate at multiple levels. However, anthropologists may disagree with the need to develop standardized measures of assessing stigma, instead recognizing that stigma takes shape in specific circumstances of culture, history, and power. In her

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<sup>1</sup> Mahajan et al., “Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward,” *AIDS* 22, suppl. 2 (2008): 69.

<sup>2</sup> *Ibid.*, 67-68.

<sup>3</sup> *Ibid.*

ethnographic research on the immune system in the United States, Emily Martin demonstrates how critical engagement of context can be a productive means of comprehending how forms of knowledge develop.<sup>4</sup>

Martin traces the shifts in logic of health and disease by showing how large-scale economic changes have had profound effects on sensibilities of personhood in America.<sup>5</sup> With the capitalist shift towards deregulation and privatization in the 1970s, “flexible specialization” emerged as a prominent objective for both labor and products.<sup>6</sup> When mass production declined and “tailor-made” production materialized, labor markets had to be able to adapt to the constant flow of workers in and out of the workforce, and products also had to quickly “adapt to the needs of production.”<sup>7</sup> Martin shows that these ideals of flexibility have become pervasive in structuring many aspects of life, from government organizations to business models, and in the realm of medicine, a commonsense view has developed in which bodies are defined by flexible immune systems that can adapt to disease.<sup>8</sup> However, Martin problematizes this new normalization of self-help through the immune system by showing how “imagin[ing] systems as inexorably evolving wholes [...can] simultaneously [set] up comparisons with other systems that cannot survive.”<sup>9</sup>

Through her ethnographic research, Martin highlights how medical concepts and practices are immersed in cultural ideas, historical forces, and the political economy, and how forms of knowledge can also have exclusionary consequences. Martin’s work in the cultural

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<sup>4</sup> Emily Martin, *Flexible Bodies: Tracking Immunity in American Culture—From the Days of Polio to the Age of AIDS* (Boston: Beacon Press, 1994).

<sup>5</sup> *Ibid.*

<sup>6</sup> *Ibid.*, 40.

<sup>7</sup> *Ibid.*

<sup>8</sup> *Ibid.*, 143-159.

<sup>9</sup> *Ibid.*, 247.



context of the United States can also help to situate my ethnography, providing a lens for analyzing how the American notions of “self-help” translate to healthcare in my fieldsite. Thus, I will evaluate the conditions in which understandings of HIV/AIDS and stigma has formed in Durham, NC. For my participants, what kinds of logic surround the disease and perceptions of those infected, and how have these forms of understanding been shaped by beliefs, politics, and history? What are the lived consequences of these worldviews?

Because context varies, multiple forms of stigma can take shape in different spaces and times, and standardized definitions and measurements may not be beneficial in combating stigma. Instead, one assessment of HIV/AIDS at a certain place may produce unintended results when transposed to another place. The universalization of a specific understanding of the disease can serve to destabilize relationships in some instances and can further exacerbate inequality in the realm of HIV/AIDS.

As Nguyen shows through his ethnographic work, international development agencies have blindly applied Western values to their response to HIV/AIDS in Western African countries.<sup>10</sup> Based on the Anglo-American model of activism, these strategies view people with HIV/AIDS as the key to fighting the epidemic through their abilities to “give a face” to the disease and to make the epidemic “real.”<sup>11</sup> Policies such as the Greater Involvement of People with AIDS (GIPA) arose to encourage people to disclose their HIV status, supposing that a shared biological disease could foster social bonds.<sup>12</sup> However in Burkina Faso and the Ivory

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<sup>10</sup> Vinh-Kim Nguyen, *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS* (Durham: Duke University Press, 2010).

<sup>11</sup> *Ibid.*, 26.

<sup>12</sup> *Ibid.*

Coast, where poverty is widespread and residents fight to survive on a daily basis, social relations are founded upon material resources rather than sharing secrets.<sup>13</sup>

Nguyen argues that international agencies have neglected these differences in context and have insisted upon training people to publicly disclose their HIV statuses, relying on the Western-based assumption of the power of public testimonials to transform, empower, and help the self.<sup>14</sup> These confessional technologies have transformed the subjectivities of both speaker and listener and have produced unintended results, undermining social solidarities while producing new forms of being in these countries.<sup>15</sup> Because agencies pay for seropositive people to speak out, who can then secure medicine and resources through these international social connections, those who engage in public testimonies have gained advantages in survival.<sup>16</sup> The commodification of confessional technologies has led to an uneven distribution in resources in the fight for life, fomenting jealousy and competition, intensifying inequalities, and creating schisms in fragile social solidarities.<sup>17</sup> Because certain lives have been visibly valued more than others, triage has become a dominant mode of treating patients, and a therapeutic citizenship has also emerged in which certain individuals can make claims for others.<sup>18</sup> Through processes of discourse, forms of relating to others have changed in Western Africa.

Similarly, Rhine has shown how the confessional technology of support groups in Northern Nigeria operates beyond the Western dream of self-help.<sup>19</sup> In a context where

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<sup>13</sup> Ibid., 83-84.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid., 33.

<sup>17</sup> Ibid.

<sup>18</sup> Ibid., 108-110.

<sup>19</sup> Kathryn A. Rhine, "Support Groups, Marriage, and the Management of Ambiguity among HIV-Positive Women in Northern Nigeria," *Anthropol Q* 82, no. 2 (2009): 369-400.

disclosure of one's HIV status can be dangerous in undermining social ties, women have appropriated a support group not to form solidarity through the disease, but rather, to arrange marriages in order to circumvent stigma.<sup>20</sup> Though the support group carries the danger of making an HIV status publicly known, the women join the group in order to find husbands, which alleviates the social pressure for marriage.<sup>21</sup> During public confrontations in which they are questioned about their marriage status, HIV-positive women must grapple with whether to disclose their disease to people who may or may not be trustworthy.<sup>22</sup> Rhine terms this response as the "management of ambiguity," in which women "actively deliberate the questions of both to whom and when they should disclose their status."<sup>23</sup> Thus, silence and secrets can be viewed as active negotiations of discourse to defy the processes of social abandonment that stigma can incur.<sup>24</sup> HIV/AIDS-related stigma has diminished the chances of a woman to fulfill the role as a wife and to gain the material benefits of having an extended family, but through complex manipulations of disclosure through confessional technologies, some women have had the ability to shape their own life trajectories in a resource constrained setting.<sup>25</sup>

Brada provides a different perspective of disclosure through her ethnographic work with HIV-positive children in Botswana.<sup>26</sup> She examines how institutionalized forms of speech are deployed in revealing diagnoses to children, which can permanently alter their mindset that HIV

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<sup>20</sup> Ibid.

<sup>21</sup> Ibid., 377-379.

<sup>22</sup> Ibid.

<sup>23</sup> Ibid., 371.

<sup>24</sup> Ibid.

<sup>25</sup> Ibid., 370-371.

<sup>26</sup> Betsey B. Brada, "How to do Things to Children with Words: Language, Ritual, and Apocalypse in Pediatric HIV Treatment in Botswana," *American Ethnologist* 40, no. 3 (2013): 437-451.

equates to death and instead ensure the children's adherence to medications.<sup>27</sup> At first, the children are conditioned to refer to their disease and medications by euphemisms such as "bad guy" and "soldier," and when pediatricians deem them ready to learn the "truth," they replace the terms with biomedical ones such as "HIV" and "CD4."<sup>28</sup> A ritualized question-and-answer dialogue about the disease, which Brada terms "disclosure catechism," takes place that "rest[s] on certain assumptions about children and about the relationships between knowledge, speech, and actions."<sup>29</sup> She designates these assumptions as "disclosure ideology" and argues that this ideology can "silence representations of the epidemic as anything other than a manageable condition in order to create a stable object of biomedical intervention."<sup>30</sup> Through the selective use of certain words over others in managing HIV patients, pediatricians have used speech to foreclose certain modes of thinking while emphasizing others, demonstrating how language can have a powerful role in shaping actions and perspectives in biomedical therapies.<sup>31</sup>

Through this ethnographic work on HIV/AIDS, anthropologists have highlighted not only the importance of situating diseases in a certain place, culture, and history, but also in the reverberating effects of the uneven deployment of discourse. I address both topics in my research, and the perspectives that Nguyen, Rhine, and Brada provide can illuminate how HIV/AIDS-related stigma operates in Durham, North Carolina. While Nguyen and Rhine have emphasized how Western notions of public testimony have altered relations in Africa, I seek to evaluate how disclosure may have changed social dynamics in a Western country. As Nguyen describes, telling one's story may be a form of confessional technology that promotes an

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<sup>27</sup> Ibid.

<sup>28</sup> Ibid., 438.

<sup>29</sup> Ibid., 437.

<sup>30</sup> Ibid.

<sup>31</sup> Ibid., 437-438.

understanding of “self-help” in which there is a “hidden truth to the self and that when this secret is shared, personal catharsis results and social bonds are formed,” and I aim to provide a more nuanced picture of disclosure in an American context.<sup>32</sup> What happens when discourse is asserted in a space where silence is institutionalized, expected, and encouraged? As I will explain later, a ritualized form of dialogue similar to what Brada alludes to has emerged in HIV/AIDS, in which society emphasizes confidentiality to protect an individual from anticipated stigma. But as Brada may ask and as I aim to address, which modes of representations become dominant and which are subsequently overlooked? Rhine shows that evaluating silence and selective modes of disclosure can illuminate power relations, so in the realm of confidentiality, how then do decisions to tell one’s story alter the self, relationships to other, and the prevailing order? These themes of confidentiality and disclosure become important in my ethnography, and I aim to highlight and question the tension between when to speak out about a diagnosis and when to remain silent.

### **Analytical Framework**

To think through the dynamics that I have observed at my fieldsite, I will draw upon several theories to better understand the processes behind HIV/AIDS-related stigma.

Firstly, what exactly is stigma? Goffman has been influential in the field of stigma research, and I will accordingly evaluate Goffman’s analysis to see how his definition has shaped our way of approaching the topic of stigma. According to Goffman, those who are stigmatized are seen as spoiled or tainted, and the stigmatized lose social status as they are discredited for

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<sup>32</sup> Nguyen, *The Republic of Therapy*, 83.

their defect.<sup>33</sup> Goffman reflects on coping mechanisms of the stigmatized, and while his perspectives on stigma can illuminate how participants may manage negative perceptions, I aim to provide a broader conceptualization of the term, one that provides a different avenue of examination in a way that does not lead us to perpetuate stigma.

Furthermore, I will consider the role of neoliberalism in shaping stigma. Theorizations of neoliberalism have been fraught with contention about how to best describe the term. In his approach to neoliberalism, Springer outlines four major understandings of neoliberalism that some have viewed as contradictory in nature:

(1) *Neoliberalism as an ideological hegemonic project*: “[E]lite actors and dominant groups [...] have the capacity to project and circulate a coherent program of interpretations and images of the world onto other,” which requires both coercion and consent.<sup>34</sup>

(2) *Neoliberalism as policy and program*: Opening up publicly owned resources to the market through the transferal “of ownership from the state or public holdings to the private sector or corporate interests” will lead to greater efficiency, and “privatization, deregulation, liberalization, depoliticization, and monetarism” are held as fundamental to the realization of efficiency.<sup>35</sup>

(3) *Neoliberalism as state form*: States deliberately participate in “processes of transformation [...] to remain economically competitive within a transnational playing field of similarly minded states,” where state capacities to provide for others are

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<sup>33</sup> Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (New York: Simon & Schuster, Inc., 1963), 1-7.

<sup>34</sup> Simon Springer, “Neoliberalism as Discourse: Between Foucauldian Political Economy and Marxian Poststructuralism,” *Critical Discourse Studies* 9, no. 2 (2012): 136.

<sup>35</sup> *Ibid.*

deemphasized while state mediations such as “social agendas centered on urban order, surveillance, immigration issues, and policing” are emphasized.<sup>36</sup>

(4) *Neoliberalism as governmentality*: Power stems from “knowledge production through the ensemble of rationalities, strategies, technologies, and techniques concerning the mentality of rule,” which produce a certain undisputed commonsense and “auto-correcting selves who facilitate ‘governance at a distance.’”<sup>37</sup>

These different manners of framing neoliberalism may seem to conflict with each other, but in my analysis, I will not limit myself to just one understanding of neoliberalism. Instead, Springer has proposed a novel way of reconciling these definitions to produce a more flexible interpretation of neoliberalism: neoliberalism as discourse.<sup>38</sup> Springer’s approach “goes beyond simply the profusion and dissemination of language that occurs either through hegemonic ideology or governmentality, and necessarily recognizes the material practices of state formation and policy and program implementation that characterize the specificities of ‘actually existing neoliberalism,’ [...] or neoliberalization in practice.”<sup>39</sup> Likewise, when I refer to neoliberalism, I will do so in this holistic manner in which common knowledge and the political economy become integral to each other in perpetuating HIV/AIDS-related stigma, as both shape our understandings and approaches to the world. While some may criticize this approach as too simplistic to do each perspective justice or too dismissive of the limitations of each understanding,<sup>40</sup> I find Springer’s approach to be a productive means of evaluating the dynamics of HIV/AIDS-related stigma, which is fraught with contingencies of disclosure. Springer

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<sup>36</sup> Ibid., 137.

<sup>37</sup> Ibid.

<sup>38</sup> Ibid., 133.

<sup>39</sup> Ibid., 141.

<sup>40</sup> Clive Barnett, “The Consolations of the Neoliberalism,” *Geoforum* 36 (2005): 7-12.

recognizes how neoliberalism is “a mutable, inconsistent, and variegated process that circulates through the discourses it constructs, justifies, and defends,” and by analyzing neoliberalism as discourse, I can address how neoliberalism not only follows a certain structure, but also more notably, allows room for agency.<sup>41</sup>

Thus, the third theory I will deploy rests on Foucault’s discourse analysis. Foucault acknowledges the power of discourse and argues that “discourse is not simply that which translates struggles or systems of domination, but is the thing for which and by which there is struggle [...]”<sup>42</sup> To gain power, institutions may attempt to control discourse through making some forms of speech normative while excluding others, but at the same time, Foucault acknowledges the influence that individuals can have in deploying their own discourse to challenge the dominant order.<sup>43</sup> In regards to HIV/AIDS-related stigma then, I will evaluate what is said and what is not said about the disease, and because discourse can also serve as an instrument of contention, I will consider how HIV-positive individuals can assert agency through the ways in which they use discourse.

Lastly, to understand the current state of HIV/AIDS as well as its progression throughout time, I will draw on scientific articles, government publications, books about AIDS and anthropology, and news articles. These sources will consider demographic information, the populations most at risk for HIV/AIDS, and the underlying factors contributing to the high prevalence rate in certain areas or groups. I will discuss this information and move from the broader contexts of the United States and North Carolina to the more specific site of Durham. I will also review government and hospital policies that affect not just those living with

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<sup>41</sup> Springer, “Neoliberalism as Discourse,” 135.

<sup>42</sup> Michel Foucault, “The Order of Discourse,” trans. Ian McLeod, in *Untying the Text: A Post-Structuralist Reader*, ed. Robert Young (Boston: Routledge & Kegan Paul, 1981), 52-53.

<sup>43</sup> *Ibid.*, 61-64.



HIV/AIDS, but society as a whole, and the sources will draw upon historical moments to address how HIV/AIDS-related stigma has developed and changed. Through this context, I hope to show how stigma stems from a complex variety of processes.

## Chapter Outline

When I spoke to one of my participants, Connie, she perceptively explained to me that stigma functions on two levels:<sup>44</sup>

*“Stigma affects two kinds of people, the person who is being inflicted upon by stigma and the person who is inflicting stigma. Stigma is like a bullseye. It is targeted at a person but has a ripple effect. People shoot to hurt someone else out of fear, ignorance, blame, and judgment, but they’re still impacted by what they’re shooting at. The shotgun has a kickback and those inflicting stigma on others are affected.”*

As Connie recognized, stigma cannot be localized to an individual, but rather, must be extended to an evaluation of society as a whole. Not only should we question how stigma touches personal worldviews, but we should also reflect on the ways in which stigma is produced and maintained. I aim to shift between a variety of perspectives in my ethnography, reflecting on the extensive construction of stigma while bearing in mind its very real, lived effects. Every chapter will begin with an ethnographic moment to illuminate the direction I will take and will be productive in illustrating my analysis. The first two chapters will focus on the mechanisms that inform and give life to stigma. Circulating ideologies and dominant policies shape stigma and the ways in which people are expected to act, and by deconstructing the basis of these institutionalized claims, we can more fully understand why stigma has remained a factor for those diagnosed with

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<sup>44</sup> Connie (retired educator) in discussion with the author, September 2013.

HIV/AIDS. In the last two chapters, I will focus on the lived experiences of HIV/AIDS to show how people respond through exploring the stories of those who function as a result of, and despite the stigma of being HIV-positive.

In Chapter 1, I will examine the national production of stigma in the realm of HIV/AIDS. By drawing upon government produced material and media examples, I will examine the history of HIV/AIDS, how the disease has progressed, and how society has changed due to its emergence to demonstrate the state of HIV/AIDS. The disease has become tied to stigma through this history, and I will attempt to provide a characterization of stigma that is dynamic and mutable. Not only has HIV/AIDS emerged in the last few decades, but neoliberalism has also become a powerful force in our everyday lives. I will discuss the role of neoliberalism in producing and reproducing poverty, disease, and stigma.

In Chapter 2, I will zoom into North Carolina to evaluate how neoliberalism, stigma, and discourse intersect at the state level. The failures of education, law, and the health system in encouraging productive discourse about HIV/AIDS can be viewed at this site, and knowledge about HIV/AIDS is masked in dialogue about abstinence and morality. In these ways, I will show how those living with HIV/AIDS are produced as privatized, isolated individuals that are separated by a mark of shame, which lies at the heart of stigma. I will also situate my work more locally by delving into Durham's history and how the past can inform the town's HIV/AIDS community today.

In Chapter 3, I will explore how stigma may be taken up in a person, producing dominant narratives in which an HIV-positive person is expected to remain silent yet must endure a journey of acceptance. These understandings are tied to neoliberal modes of thinking, and by

evaluating the lived experiences in the realm of this governing ideology, we can examine how certain forms of discourse gain power while others voices are silenced.

In Chapter 4, I will explore how HIV-positive individuals in the community have responded to the stigma in complicated ways. These responses are not just coping mechanisms but rather empowerment through discourse, and I will draw upon Foucault's work to highlight the potential of asserting discourse. Though expected to keep their diagnoses a secret, people can find ways in regaining power through their voice, and in doing so, they emphasize the ties to others to show that they are not alone in their disease. We cannot narrowly define stigma and assume that it has universal effects. Neoliberal rationales may affect their decisions in remaining silent or disclosing their diagnosis, but ultimately, I will show the agency that people can claim in forging their own identities and the ways in which they can reconfigure power relations by no longer consenting to remain silent. At the same time, it is important to recognize that voice is embedded in politics as well, and I will question the dual emancipatory and oppressive roles of discourse.

## Chapter 1: National Contingencies of HIV/AIDS

### Deciphering Science

When I walk into the venue for the HIV Treatment meeting, I am surprised to see neatly lined rows of tables punctuated with a notepad and pen at each seat. From what Irene had told me earlier, I had assumed that the meeting would be a casual information session for the community, but the carefully placed pens and paper hint at a formality that I was not expecting. I pick a seat and greet others nearby, and when everyone has settled down, a smartly dressed speaker opens up the meeting with a PowerPoint slide of the main speaker's credentials. Everyone claps as Dr. Matthews takes the podium.

Standing in the front of the room, Dr. Matthews conducts the meeting in a lecture-style format and systematically goes through each bullet points in his slides. He cites statistics on the demographics of the clinic he works at before proceeding through a series of acronyms that demonstrate the progress of his clinical trials. EMDOC, CTU, ACTG, IMPAACT, CRS. Within a short period of time, I become confused with the meaning and significance of each abbreviation, and I wonder whether the rest of the audience is as lost as I am. No one raises a hand to ask a question, so Dr. Matthews flips to the next slide, describing the various categorizations of HIV/AIDS drugs based on mechanisms such as nucleoside inhibitors. Having learned these terms from my microbiology class, I am proud that I can conjure at least a rough semblance of what his words mean. But then, he becomes even more technical as he addresses the new HIV/AIDS drugs being studied. Tenofovir alafenamide, GSK 1265744-CAP, nanonparticles? My excitement quickly evaporates. As I look around the room, everyone else has the same blank expression on their faces. I notice that I am the only one in the audience furiously scribbling notes down in my notebook.

However, the atmosphere abruptly shifts when Dr. Matthews discusses the real life applicability of one of the new drugs. He reveals about GSK 1265744-CAP, “We all know some of our friends are struggling to take their meds, so if we can have this as a one time a month injection, it would be fantastic.”

Instantly, the community members in the room become animated and nod in collective agreement. Always vocal and inquisitive, Irene raises her hand to ask the first question, “Are these drugs for people who are basically infected, or can they be used to keep people from getting infected?” Dr. Matthews reassures Irene that this form of injection is “especially attractive for prevention” and “good for high risk and non-adherence people.”

By that moment, people in the room are talking over each other in their excitement about the potential of this drug, and they begin to question Dr. Matthews about the drug’s ability to change the landscape of HIV/AIDS. One of the attendees asks Dr. Matthews how long the drug is expected to last for. Becoming visibly uncomfortable at this escalation of hope, Dr. Matthew’s face turns red and emphasizes, “It’s all speculative. I don’t want to put the wagon in front of the horse.”

As the meeting moves beyond the slide on new treatments, the dynamics between the speaker and the attendees follow the same pattern that I have described: Dr. Matthews speaks in technological, clinical terms while the community members ask questions about the relevance of his slides to their own lives and the lives of their friends. This ethnographic moment illuminates how certain conversations on HIV/AIDS can become mismatched. Increased information about the disease does not necessarily translate into altered approaches to dealing with HIV/AIDS, which I will address later in this chapter.

As Dr. Matthews too readily emphasizes in his presentation, HIV is a virus that attacks individual bodies through specific cells. This scene also demonstrates, though, that the scientific source of the disease is not what is at stake for the rest of the community. Instead, HIV/AIDS affects their lives in large-scale ways, and understanding the disease and its implications requires a broader look at the complex contingencies of history, politics, economics in the United States. While science can reveal the biological mechanisms behind the disease, medical anthropology fills in the picture with considerations of context, showing how biology and society are connected yet often overlooked in our worldviews. Reducing the disease to just one discipline would ignore the complicated ambiguities and embodied consequences of living with HIV/AIDS. With this medical anthropology approach in mind, I will evaluate how HIV/AIDS operates at the national level, and then I will zoom back in to explore the consequences HIV/AIDS in a southern town. In this chapter, I will focus on national productions of the disease, and with the framework in place, the subsequent chapter will explore how these national ideologies of HIV/AIDS are further articulated and mediated in Durham, North Carolina. A certain reasoning exists behind stigmatized diseases that enforces social norms and perceptions, inevitably marginalizing some while empowering others. We can begin to understand how stigma functions by disentangling the multiple layers of knowledge and power in the nuanced spaces of HIV/AIDS.

### **The Changing State of HIV/AIDS in America**

On June 5<sup>th</sup>, 1981, the United States Centers for Disease Control and Prevention (CDC) published a report detailing the occurrence of a rare lung infection in five young, previously

healthy, gay men in Los Angeles.<sup>45</sup> Media outlets such as the Associated Press and the Los Angeles Times picked up on the report, and as news of the cases spread, doctors from across the nation began to flood the CDC with similar cases.<sup>46</sup> By the end of the year, 270 cases of severe immune deficiency among gay men had been reported, and while fear and mystery shrouded the disease, scientists, doctors, and the public alike understood that the disease was quick and deadly. Of the 270 cases, 121 people had died by year's end.<sup>47</sup> Furthermore, because these cases primarily affected gay men, the media and health-care workers began to refer to the disease as Gay-Related Immune Deficiency (GRID).<sup>48</sup>

Dr. Sanders, a nurse practitioner with multiple degrees, began to work with AIDS patients in the 1980s in Washington, D.C, which had the highest AIDS rate of any city in the United States at that time. He described the clinical scene during the days when knowledge about AIDS was limited:<sup>49</sup>

*“Back then, there were minimal treatment options. We had to manage symptoms rather than treat them, and there was a societal view that there was a marginalized group of people deserving of what they got. I heard one of the nurses say about a patient, ‘If he wasn’t a fag, he wouldn’t have gotten HIV.’ Surgeons were also afraid to do surgery on gay people because they were afraid of getting AIDS.”*

Even those who were responsible for caring for the sick were actors in perpetuating the stereotypes, blaming gay individuals for their disease. Because the prognosis for having AIDS

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<sup>45</sup> “A Timeline of AIDS,” AIDS.gov, accessed December 3, 2013, <http://aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline>.

<sup>46</sup> Ibid.

<sup>47</sup> Ibid.

<sup>48</sup> Patricia Whelehan, *The Anthropology of AIDS: A Global Perspective* (Gainesville: University Press of Florida, 2009), 11.

<sup>49</sup> Dr. Sanders (nurse practitioner and researcher) in discussion with the author in November 2013.

was dire and people did not understand how the virus spread, fear shrouded the disease. Relating fear to stigma, Dr. Sanders proceeded to say,<sup>50</sup>

*“Infectious disease have created public fear—the fear of contagion, and fear is the foundation for stigma.”*

This historical fear of contamination propagated through instances of limited knowledge and contributed to the stigma of HIV/AIDS as a primarily gay disease. By the end of 1982, the CDC officially began to the sickness Acquired Immune Deficiency Syndrome, describing AIDS as “a disease at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known case for diminished resistance to that disease.”<sup>51</sup> Although this definition focused on the biological aspects of AIDS, the social label of GRID, a “gay white boys” disease, had already imposed onto biology, translating to consequences for the body.<sup>52</sup> AIDS was frequently misdiagnosed or under-diagnosed, for the public often presumed that all gay men and only gay men could contract the disease.

The past has informed public perceptions of the disease to this day, and when I asked my interviewees about how people living with HIV/AIDS are seen, many pointed out that stigma primarily affects the gay community. Because of this bias, Irene was surprised when she received her diagnosis.<sup>53</sup>

*“It was a big shock to me. I had heard that gays and prostitutes could get it—I didn’t think I could get it. I had only been with this man twice.”*

Since she was not aware of AIDS affecting anyone but men who have sex with men and sex workers, she did not see herself to be susceptible to the disease and did not realize that she

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<sup>50</sup> Ibid.

<sup>51</sup> “A Timeline of AIDS.”

<sup>52</sup> Whelehan, *The Anthropology of AIDS*, 207.

<sup>53</sup> Irene (HIV-positive participant) in discussion with the author in September 2013.



should get tested. This misunderstanding increased her risk of contracting HIV as well as her risk of going undiagnosed until her health deteriorated to an extent that would be more difficult to recover.

A few months after terming the disease as AIDS, a case emerged that stood out from the norm: an infant had contracted AIDS through a blood infusion.<sup>54</sup> Similar cases of infected blood transfusions emerged, and the CDC began to develop occupational exposure precautions.<sup>55</sup> The CDC was able to identify the major transmission means and ruled out other channels that had contributed to the fear.<sup>56</sup> No longer could the spread of the disease be attributed to casual contact with an infected individual through food, water, air, or environmental surfaces.<sup>57</sup> In 1984, scientists in Paris made another breakthrough and isolated AIDS to the Human Immunodeficiency Virus.<sup>58</sup> This scientific discovery, coupled with patient cases that did not confine with the norm of AIDS as a gay disease, spurred research to gain more information about the disease.<sup>59</sup> By 1985, the first HIV antibody test had been developed, and in 1986, the first antiretroviral medications were released.<sup>60</sup> As time passed, more technologies and medicines have become available to treat HIV so that the virus may never progress to AIDS, but what do the increased abilities to understand and care mean in relation to stigma?

### **Conceptualizing Stigma**

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<sup>54</sup> “A Timeline of AIDS.”

<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

<sup>57</sup> Ibid.

<sup>58</sup> Ibid.

<sup>59</sup> Ibid.

<sup>60</sup> Ibid.

Although I have used the term “stigma,” I have yet to fully describe the word and its implications. I will now detour to explore the various meanings of stigma and to arrive at a concept that will be used throughout this research. I do not wish to define the word; rather, I hope to illuminate the multiple connections that the term invokes.

Scientifically, HIV is similar to other infectious diseases such as the flu in that infection requires complicated cell interactions and takeover. Socially, though, HIV/AIDS may be a more complex issue. HIV is primarily spread through contact with a positive individual via unprotected sex and intravenous drug use, and these transmission means have led to associations of HIV with promiscuous sexual activities and illicit drug using behavior.<sup>61</sup> Because these modes of viral transmission evoke strong cultural responses about what is right and wrong, collective judgments on the ethics of HIV-positive individuals transpire.<sup>62</sup> The morality judgments are compounded with misunderstanding of how the disease spreads, as some still believe that HIV can be contracted through casual contact with seropositive individuals. Questions of virtue, coupled with a history of misinformation and public fear, has led to a culturally constructed stigma that shrouds the topic of HIV/AIDS and shapes the discourse surrounding the disease. Subjected to public scrutiny, those living with HIV/AIDS may be viewed as fundamentally incompatible with those who are not infected. In these ways, the healthy oftentimes look down upon, are fearful of, and may even blame others for becoming infected with HIV, and the stigma associated with HIV/AIDS can hinder prevention efforts and discourage people from being treated.

Stigma can have variable consequences for those living with the disease. Researchers have demonstrated how due to stigma, people living with HIV/AIDS can face discrimination that

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<sup>61</sup> Whelehan, *The Anthropology of AIDS*, 234-235.

<sup>62</sup> Ibid.

is self-imposed, through other individuals or even through institutions.<sup>63</sup> Those who are most at risk of infection, such as drug users, sex workers, homosexual men, minorities, women, and the impoverished, face pre-existing inequality and stigma due to their circumstances. People may be afraid to get tested for HIV in fear of positive results and further negative societal judgment, especially if they do not have the means to seek adequate treatment to become healthy once again. Even though medication can improve the health of HIV-positive individuals, this does not necessarily indicate that they will have the resources to access care.

Although stigma generally involves these characteristics and implications, the more specific aspects of stigma are different depending on location and time, and many of the past scientific efforts at understanding stigma have neglected these differences. Scientific studies of stigma are often focused on how the stigma is internalized by the affected individual, but these studies have left out the other key players in stigma construction.<sup>64</sup> They rarely mention the power that institutions can have in creating and maintaining stigma and also how AIDS-related stigma is a society's joint reaction to a disease. Instead, these studies have appropriated Goffman's conceptualization of stigma for their own purposes, briefly describing stigma as if it is singular and universal. In these studies, the explanation of stigma draws from Goffman and reads in a manner similar to this: stigma is "an attribute that is deeply discrediting" and reduces the stigmatized person "from a whole and usual person to a tainted, discounted one."<sup>65</sup> These studies condense Goffman's conceptualization of stigma into one or two phrases, and they proceed as if everyone has the same understanding of the term and as if stigma affects people evenly, failing to consider context.

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<sup>63</sup> Mahajan et al., "Stigma in the HIV/AIDS epidemic," 71-72.

<sup>64</sup> Ibid., 70.

<sup>65</sup> Yang et al., "Culture and Stigma: Adding Moral Experience to Stigma Theory," *Social Science & Medicine* 64 (2007): 1525.

Goffman was undoubtedly influential in first defining the term, and his work has propelled a more intense study of stigma and has led to more nuanced understandings of how to characterize stigma. However, researchers have mainly used his discussion of stigma to examine the psychological effects on individuals, ignoring the social conditions that the term is embedded in. Stigma is pinpointed to the individual body without consideration of the various power dynamics that inform these experiences. Certain conditions exist so that some people have the ability to stigmatize while others face stigmatization, and this is the space in which anthropology can be productive. Ethnography explores the broader connections and unique social processes that continually inform stigma, and anthropology has contributed to the study of stigma by analyzing the ways in which stigma threatens the capacity to hold on to what matters most to ordinary people in everyday life, such as jobs, wealth, relationships, health, and life chances.<sup>66</sup> Stigma does not solely involve psychological manifestations, and instead, this concept draws upon a multitude of actors and processes that ultimately translate into variable lived experiences. My research will also aim to provide a broader picture of the concept of stigma that involves both those who are infected by HIV/AIDS and those who are not.

When I first began my fieldwork, I was careful of using the word “stigma” in my interviews. I did not want to assume that stigma was uniformly perceived and experienced, and I asked all of my participants whether they believed HIV/AIDS-related stigma existed. As my research progressed, however, I discovered that although stigma was assumed to blanket the HIV/AIDS community, many of my participants who are living with HIV did not just relate stigma to their own bodies. They expressed the existence of stigma, but they also demonstrated how stigma can be variably negotiated in the ways they confront the world. What are the

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<sup>66</sup> Ibid., 1528.

conditions in which stigma is held to be a common sense factor of HIV/AIDS, yet is mutable in the ways people experience stigma?

My research analyzes the terrain in which this question is precipitated, such that society ultimately advocates for concealing diagnoses to mitigate stigma instead of finding ways to confront these perceptions. As Dr. Sanders, one of my participants, expressed,<sup>67</sup>

*“The literature suggests that stigma is just part of the experience of being HIV-positive, whether anticipating the stigma or experiencing it. Until we have no more new infections and no more AIDS cases, people can live their natural lives and die with AIDS. Until we have a cure for HIV/AIDS, stigma will be part of the experience.”*

A nurse with many years of institutional experience, Dr. Sanders constantly referenced what “the literature suggest[ed]” in our interview, and he presumed stigma to be an inevitable and immutable characteristic of HIV/AIDS. I argue that this dialogue of a permanent stigma has power in shaping the lives of those living with the disease, and everyday actions and policies serve to enforce the stigma by encouraging confidentiality for those who are positively diagnosed. Through this silence, the perception that one is alone in the disease propagates, and instead of questioning why the stigma exists in the first place, the idea that one must remain silent for protection becomes further reinforced. Although individuals with HIV/AIDS may face constraints in these ways, I will also show how they can demonstrate agency in their negotiations of when to speak out and in what circumstances, reclaiming their voices in their connections with others by these acts of self-empowerment.

As seen, the term stigma does not merely convey a “spoiled identity” onto a person who stands out from societal norm. Rather the word and the act encompass multifaceted conditions,

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<sup>67</sup> Dr. Sanders (nurse practitioner and researcher) in discussion with the author in November 2013.

and while the meaning of the word is shaped and reshaped by people, the term also influences perceptions and actions in society. Thinking of stigma requires considerations for those who are infected and affected by HIV/AIDS, namely everyone, as well as the broader ideologies and processes embedded in stigma. With the complexity of this term in mind, I will return to the historical terrain of HIV/AIDS to further explore the relationship of stigma to struggles of power through the control of discourse and knowledge.

### **Media, Activism, and Education in America**

In the 1980s and 1990s, activists for HIV/AIDS advocated for equal rights and fought the notion that AIDS was a gay disease, filing lawsuits for AIDS discrimination and attending forums to raise awareness.<sup>68</sup> The term GRID (Gay Related Immune Disease) had initially contributed to the stigma surrounding HIV/AIDS as a gay disease, showing how language can be powerful in shaping societal perceptions, and during this period of activism, agents could be seen in a continual struggle to assume influence through the manipulation of discourse. In the Second National AIDS Forum, attendees issued what is now known as “The Denver Principles,” which advocated for replacing the label “AIDS victims” with “people living with AIDS” (PLWA).<sup>69</sup> They hoped that by restyling the discourse around the disease, they could also reshape stigma.

In a time when HIV diagnoses led to intense fear and morality judgments, the ability to speak out about living with HIV/AIDS also conveyed a certain kind of courage and control. Figures such as Ryan White and Magic Johnson emerged as the faces of the disease, publicizing the disease so as to give a voice to the otherwise silent people living with HIV/AIDS. These voices come with a context as well.

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<sup>68</sup> “Timeline of AIDS.”

<sup>69</sup> Ibid.

Ryan White was a teenager who contracted AIDS through contaminated blood products, and when his school found out about his diagnosis, they refused to let him attend.<sup>70</sup> The media picked up on this story, and as this case received international attention, Ryan and his mother spoke out about discrimination and advocated for change and understanding.<sup>71</sup> Even though Ryan eventually died of AIDS, he left a legacy in his name: Congress passed the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act shortly after his death.<sup>72</sup> This legislation provides funding for individuals living with HIV/AIDS with no insurance so that they can receive healthcare.<sup>73</sup>

Earvin “Magic” Johnson, a famous basketball player, stunned the nation with the revelation of his HIV diagnosis in 1991. On camera, Magic addressed the world: “Because of the HIV virus that I have attained, I will have to retire from the Lakers.”<sup>74</sup> Many people were shocked that someone who was not gay and who seemed so healthy could have contracted HIV, and the news headline for *Time Magazine* even read “Health It Can Happen to Anybody. Even Magic Johnson.”<sup>75</sup> Magic developed a charity in his name to raise awareness for HIV, and since his disclosure, many have claimed that Magic has changed the perception of what it means to live with the disease and who could be susceptible to HIV.<sup>76</sup>

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<sup>70</sup> “Who Was Ryan White?”, accessed December 3, 2013, <http://hab.hrsa.gov/about/hab/ryanwhite.html>.

<sup>71</sup> Ibid.

<sup>72</sup> Ibid.

<sup>73</sup> Ibid.

<sup>74</sup> Rick Weinberg, “7: Magic Johnson Announces He’s HIV-positive,” accessed December 2, 2014, <http://sports.espn.go.com/espn/espn25/story?page=moments/7>.

<sup>75</sup> Sam Gregory, “Magic Johnson and HIV: The Lasting Impact,” *Time*, November 7, 1991, accessed December 3, 2013, <http://keepingscore.blogs.time.com/2011/11/04/magic-johnson-and-hiv>.

<sup>76</sup> Ibid.

While both Ryan and Magic were courageous in their efforts to fight stigma in times of extreme discrimination, their public fame was contingent upon the power of the media and money. Selected to be representatives by institutional powers, these public figures had the influence to provide a voice to others. They had the ability to become visible and to have their stories heard without facing public rejection for having HIV, having a place in history and in the future through their namesake legislation and foundation that will continue even with death. What about the other voices in the nation, though, those who were not heard? Not everyone has the support to speak out, and the everyday lived experiences of HIV/AIDS are laced with dynamic struggles for individual agency in conflicts of disclosure, which my research aims to address. Some discourses are more prominent than others, but ultimately, people can employ discourse in variable ways for the power to change relations.

Furthermore, as these historical events show, the revelation of knowledge or the limitation of information has been key in shaping the perceptions of HIV/AIDS and contributing to stigma. Although society may appear to have increased facts about HIV and more spokespeople to represent the disease, this type of knowledge does not necessarily translate to the eradication of stigma. Many of my participants expressed that although HIV/AIDS is less heavily stigmatized now as compared to the past, stigma still exists. Irene expressed disappointment in this negative correlation,<sup>77</sup>

*“You can always tell someone you got diabetes. You can tell them you have cancer. But you can’t tell them you have HIV because you just can’t do that—you can’t call in sick with HIV. Even with all the education, it’s sad.”*

Many prevention efforts have been focused on educating the public, but these broad and sweeping intervention strategies have not affected much change in public attitude or in

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<sup>77</sup> Irene (HIV-positive participant) in discussion with the author in September 2013.



mitigating stigma. A study published in 1999 revealed that nearly 1 in 5 American adults still “feared” persons with AIDS even after years of education efforts.<sup>78</sup> Seemingly, the level of stigma has stabilized and will remain regardless of the amount of information that is propagated throughout society. What exactly about HIV/AIDS keeps the stigma alive, and how does the production of discourse on the national and local level contribute to maintaining negative public perceptions? To answer this question, I will explore how national policies and ideologies have shaped healthcare today.

### **The Response of the U.S. Government to HIV/AIDS**

In 2010, the White House released the National HIV/AIDS Strategy for the United States, citing three main goals to reduce the number of HIV infections:

1. “Intensify HIV prevention efforts in communities where HIV is most heavily concentrated.”<sup>79</sup>
2. “Expand targeted efforts to prevent HIV infection using a combination of effective, evidence-based approaches.”<sup>80</sup>
3. “Educate all Americans about the threat of HIV and how to prevent it.”<sup>81</sup>

With this federal strategy in place, the Centers for Disease Control and Prevention has become a trailblazer in the realization of these goals. The CDC has developed various programs aimed at reducing HIV infections, from promoting condom distribution to providing funds to local health departments, and we can also see many local efforts made to fundraise for and raise awareness of

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<sup>78</sup> Gregory M. Herek, John P. Capitanio and Keith F. Widaman, “HIV-related Stigma and Knowledge in the United States: Prevalence and Trends, 1991–1999,” *American Journal of Public Health* 92 (2002): 371–377.

<sup>79</sup> “National HIV/AIDS Strategy for the United States,” last modified July 2010, <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>.

<sup>80</sup> Ibid.

<sup>81</sup> Ibid.

the real health concern that HIV/AIDS presents.<sup>82</sup> As I mentioned in the introduction, we even have races dedicated to raising awareness, and condoms and brochures were not in short supply at the 5K I attended.

With all these intervention strategies and community outreach programs present, surprisingly, the number of people living with HIV has still risen significantly in the last decade while the annual number of new HIV infections has not changed. According to the CDC, “[m]ore than 1.1 million people in the United States are living with HIV infection, and almost 1 in 6 (15.8%) are unaware of their infection.”<sup>83</sup> These statistics are startling, as they reveal a detrimental disconnect between the intended plans and the actual results.

The National HIV/AIDS Strategy has education listed as their third goal, and Connie, one of my participants who used to work in schools, summed it up best: “the denominator that minimizes fear is knowledge.”<sup>84</sup> Surely, if education about HIV/AIDS transmission is so important, why has knowledge about HIV/AIDS not affected prevention and the rates of new HIV infections? While every one of my participants has mentioned how education is imperative, they have also voiced that they believe education has been ineffective in two ways: by the lack of sex education and by the lack of application of knowledge to behavior.

Connie expressed her disappointment in the education system, telling me,<sup>85</sup>

*“We can’t do anything about it if we don’t do something prior to educate. We are taking sex out of school. We tell people that if you are having sex, you are blank, and if you don’t, you are blank. If we don’t have education, how can we equip ourselves?”*

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<sup>82</sup> “HIV/AIDS Programs,” accessed December 4, 2014, <http://www.cdc.gov/hiv/prevention/programs/>.

<sup>83</sup> “HIV in the United States: *At a Glance*,” accessed December 4, 2013, <http://www.cdc.gov/hiv/statistics/basics/ata glance.html>.

<sup>84</sup> Connie (retired educator) in discussion with the author, September 2013.

<sup>85</sup> Ibid.

Because teenagers are considered high risk, the lack of sex education available to them have implications on their sexual behavior, and many may not understand the importance of condom use, HIV testing, and how to receive care for a diagnosis. Not only have schools avoided discussions of safe sex, but this evasion also relates to the general taboo of speaking about sex in society.

Connie continues,<sup>86</sup>

*“We have a gap in our health education and awareness system. No one wants to acknowledge that people are having sex, as if giving out the information will make them want to have sex, as if you would go to Hell if you talked about it—and it’s problematic. We can talk about how many people are getting blown up in Afghanistan and who to kill next, but we can’t talk about anything that has to do with our personal lives.”*

Certain discourses about abstinence and morality overshadow the discourses about how to engage in safe sex. By failing to initiate the appropriate dialogue about sex and sexual diseases, people may partake in risky behavior without realizing it. This highlights the importance of dialogue in the realm of HIV/AIDS, which I will go into more detail in later chapters.

Not only is knowledge about the disease lacking in its value in prevention, but the knowledge has come to a standstill in the ability to affect perception as well. Even with more detailed information about how HIV/AIDS spreads since the disease’s emergence, this knowledge is not always internalized and may not necessarily change beliefs or attitudes. In a study conducted by the Kaiser Family Foundation in 2006, researchers discovered that about 37% of Americans continue to believe that someone can contract HIV from kissing, and 22% of Americans believe that HIV can be obtained through sharing a drinking glass.<sup>87</sup> While 16%

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<sup>86</sup> Ibid.

<sup>87</sup> Henry J. Kaiser Family Foundation, “Attitudes about Stigma and Discrimination Related to HIV/AIDS,” *Kaiser Public Opinion Spotlight* (2006).

believed that touching a toilet seat could transmit HIV, 12% of people thought that swimming in the same pool could also lead to HIV.<sup>88</sup> People still hold onto fear and misconceptions of people living with HIV/AIDS, which sustains stigma.

Tim, who is HIV-positive, told me why he does not think education efforts are effective in preventing HIV/AIDS and changing action:<sup>89</sup>

*“It’s easy to read out of a book about what’s going on, but experience is best. It’s better to hear first hand from someone who has experienced it. I went to 30-40 rehab centers and they didn’t work because they were telling me what they read out of a book.”*

By leaving out the human implications of the disease in the education of HIV/AIDS that is available, a certain discourse is missing in the discussion of HIV/AIDS, and Tim ultimately believes that there are limitations to the knowledge that is present in the world.

Besides education, what about the number 1 and 2 goals of the National HIV/AIDS Strategy? What about intensifying and expanding prevention efforts in the most affected communities? My participants have expressed how government support is lacking for HIV/AIDS programs, which could be why the disease is still a significant health problem and consequently why stigma remains a societal issue. When I spoke with my interviewees, I asked everyone whether they believe the government is doing an adequate job of tackling HIV/AIDS. They all responded similarly: no, more can be done. The funding for HIV/AIDS support programs is not adequate, and agencies do not reach the populations they need to. Thomas told me that the government is cutting back on funding for his medications so that he has to pay out of pocket, and Cassie, another educator, expressed that the government is especially doing a poor job in targeting the lower socioeconomic communities. Both are concerned with problems related to

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<sup>88</sup> Ibid.

<sup>89</sup> Irene (HIV-positive participant) in discussion with the author in October 2013.

HIV/AIDS that are contingent on money or the lack thereof, and to understand the issues with funding, we must explore the ideology and policies of neoliberalism that have swept the nation and have had reverberating effects on everyday life.

### **Neoliberalism in Healthcare**

The idea of liberalism first emerged in the 1770s when Adam Smith “advocated for a minimal role of government in economic matters so that trade could flourish.”<sup>90</sup> Influential until the turn to Keynesian economics in the 1930s, the United States’ involvement in the world wars created the conditions that allowed for the government to have a more prominent role in the economy.<sup>91</sup> However with the 1970s, the nation began to face rising unemployment and accelerating inflation, and liberalism reemerged as the solution for this discontent. People once again began to “cry for deregulation, privatization and deletion of government intervention in the market economy.”<sup>92</sup> This was a time of renewed liberalism, or neoliberalism.

Neoliberal ideals rely on the assumption that the “free functioning of the market forces leads to a better utilization and allocation of resources, guarantees a better satisfaction of the requirements of consumption and bigger balance of the foreign trade, and altogether produces higher economic growth and therefore development.”<sup>93</sup> This invisible hand of the market, operating without regulation, is thought to lead to the greatest prosperity for the greatest number of people.<sup>94</sup> Neoliberalism thus emphasizes the control that individuals have, a free market via

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<sup>90</sup> Sue McGregor, “Neoliberalism and Health Care,” *International Journal of Consumer Studies* 25, no. 2 (2001): 83.

<sup>91</sup> *Ibid.*

<sup>92</sup> *Ibid.*

<sup>93</sup> *Ibid.*, 82-84.

<sup>94</sup> *Ibid.*

privatization and deregulation, and decentralization of the national government to state and municipal powers.<sup>95</sup>

This neoliberal mindset has led to cuts in government funding and the privatization of healthcare, which can be problematic in many ways. Ignoring unequal social and cultural circumstances, neoliberalism leads to expectations in which the poorest people are required to find their own solutions to healthcare. Because people are expected to take responsibility for the self, those who cannot find their way into the market are blamed for their failures, which are attributed to poor personal choices rather than greater constraining structures. Healthcare is no longer a public good that should be available for all, but a private good only for those who can afford it. Instead of attempting to fix the government or inspiring social change towards a more equal society for all, society comes to rely on consideration only for the self. In these ways, neoliberalism can propagate social inequality and lead to an unequal burden of disease for those at a lower socioeconomic status, as those who are most at risk and in most need of care are denied access to services.

From their website, the CDC claims to “provide national leadership and support for the implementation of a high-impact prevention approach to reducing new HIV infections by using combinations of scientifically proven, cost-effective, and scalable interventions and prevention strategies directed towards the most vulnerable populations in the US who are most affected by, or at greatest risk for, HIV infection.”<sup>96</sup> Interestingly, the CDC expresses the desire to implement plans that are “cost-effective,” another sign of how neoliberal rhetoric has come to saturate our daily lives. Neoliberal policies that focus on privatization and deregulation have led to the commodification of health, such that considerations of the economy and the market are

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<sup>95</sup> Ibid.

<sup>96</sup> “HIV/AIDS Programs.”

significant even when lives are at risk. By adding “cost-effective” to their description of their strategies, the CDC gives the impression that their policies will reflect those of financial corporations in which doing business is a numbers game—optimization entails reaching the most people for the least amount of money. However, the term “cost-effective” can also lead to subjective analyses of what results are needed in order to justify the cost. Does “most effective” entail merely reaching out to the most people (such as giving away condoms to the most number of people) or directly changing the behavior of people so they are less at risk? Do these strategies consider that some people are more at risk than others, which is dependent on location, and also that some people may be more sick than others?

Through this emphasis on economics in policies, populations are grouped for intervention or denied help based on considerations of money. Sweeping interventionist strategies, always mindful of cost and efficiency, ignore individual and localized considerations of the needs of the target population. In healthcare, these neoliberal methods also coincide with biopolitics, in which power intervenes to control life through managing who can and cannot receive medicine and access to care. Although I will not go into depth about biopolitics, it is important to acknowledge how the government can be influential in their ability to maintain social hierarchies through the control of health opportunities. Some people are excluded from life while others are allowed to live, and combined with a neoliberal rationale in health, those in power can solidify the conditions of the poorest and sickest groups.

Furthermore, while the National HIV/AIDS Strategy aims to educate people about the “threat” and “prevention of the disease,” the strategy does not mention the stigma that people face. This national approach remains silent about the societal construction of the disease while emphasizing the individual’s task to become educated about HIV in order to remain HIV-free.

Although many of my participants expressed that the ineffectiveness of HIV/AIDS prevention efforts stems from a lack of sex education and the inapplicability of the information available, few acknowledged the differential access to knowledge.

Notions of personal responsibility pervade American culture even in education, and Martin shows in her ethnographic work how learning in the United States is hinged on processes of social differentiation.<sup>97</sup> She evaluates educating and training in the body, drawing upon Guillory's work on the American school as an institution.<sup>98</sup> Schools reproduce the social hierarchy because they are based on distributing cultural capital unequally: only those who have money can buy into education.<sup>99</sup> Individuals thus have the responsibility to invest in one's own education to acquire flexible skills, and Martin demonstrates how education leads to variation in bodies in which some people have "superior immune systems, superbly trained and continuously reeducated to respond flexibly to any new circumstance in the environment" while others are hindered by "slow, rigid, inflexible immune systems."<sup>100</sup> In these ways, the American preoccupation with education as the solve-all problem for HIV/AIDS can serve to reproduce social inequalities by placing the responsibility on the individual to access information. The medical system in place emphasizes knowledge of the body and diseases, but inevitably, some will not have the means to become educated and will consequently be held liable for their infection and will be excluded from care.

This neoliberal approach the economy, education, and healthcare ultimately translates to effects on action and perceptions in the realm of HIV/AIDS, having consequences that may not necessarily fulfill CDC's mission to reduce infections. Without the proper channels of support in

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<sup>97</sup> Martin, *Flexible Bodies*, 201-202.

<sup>98</sup> Ibid.

<sup>99</sup> Ibid.

<sup>100</sup> Ibid.



care from the American government, those with less socioeconomic resources are thus put at a higher risk of contracting HIV/AIDS.<sup>101</sup> For example, a lack of stable housing has been linked to increased risk for infection.<sup>102</sup> Once a person contracts the disease, a positive status also leads to discrimination at the workplace, less access to regular medications, and possibly a diminished ability to work due to the health toll of the virus.<sup>103</sup> Due to neoliberal policies, economic inequalities transform into health inequalities, further reinforcing each other. The poor remains poor, and the sick remains sick.

Neoliberal attitudes of individualism also place the blame on HIV-positive patients, both constructing the underlying foundation of stigma and fueling the misunderstanding. As described before, the ways of contracting HIV have become laden with morality judgments, and people who are HIV-positive become stigmatized as dirty and immoral. In a survey conducted by the Kaiser Family Foundation in 2002, they asked participants to agree or disagree with this statement: “In general, it’s people’s own fault if they get AIDS.”<sup>104</sup> The number of people who agree with this statement has increased from 33% to 40% since 1990.<sup>105</sup> This positive trend in moral condemnation is disturbing and affects the longevity of stigma. People may be afraid to get tested for HIV in fear of the negative societal judgment or due to a lack of resources, continuing the possibility for high-risk behavior. Thus, the cycle of disease, stigma, and

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<sup>101</sup> Nancy E. Adler, “Overview of Health Disparities,” in *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*, eds. Gerald E. Thompson, Faith Mitchell and Monique B. Williams, (Washington: National Academic Press, 2006).

<sup>102</sup> Aidala et al., “Housing Status and HIV Risk Behaviors: Implications for Prevention and Policy,” *AIDS and Behavior*, 9 (2005).

<sup>103</sup> Whelehan, *The Anthropology of AIDS*.

<sup>104</sup> Henry J. Kaiser Family Foundation, “Attitudes about Stigma and Discrimination Related to HIV/AIDS.”

<sup>105</sup> Ibid.

inequality continues to spin in the space of neoliberalism, and in the next chapter, I will ask how these national neoliberal ideals affect my participants in Durham, North Carolina.

## **Chapter 2: From the United States, to North Carolina, to Durham- Circulating Ideologies, Economies, and Politics of Disease**

### **Ruptures Between National, State, and Local Politics**

After my afternoon class, I rush to my car so that I can drive to Irene's house to give her a ride. I am supposed to go to a meeting at AIDS Alliance, which is an organization that serves HIV-positive individuals by providing funding for hospital visits, medications, utility bills, food, housing, prevention services, and testing. The meeting is beginning in less than thirty minutes, and I am running late. When I check my phone, I notice that I have a missed call from Irene, so I promptly dial her number.

"How would you feel about picking up Rhonda?" she asks me when she answers. She proceeds to explain how Rhonda's ride to the meeting has cancelled on her at the last second, and now Rhonda is currently stuck at the library. I had met Rhonda at the support group a few weeks earlier, and understanding Rhonda's sensitive nature, I am worried that she is upset.

"Of course I can! That's no problem at all," I respond to Irene.

Having a car is one of the benefits I enjoy in conducting my research. Time and time again, I am reminded of how lucky I am to be able to travel from place to place without worries of when the bus ran, how far away the bus stop is, and what bus routes to take. I am more than happy to be able to help my friends with transportation, even if it is only for a brief moment. I frequently travel to participants' houses, the support groups, and the meetings, and besides being able to easily reach my participants, I am also able to have intimate talks with people in the car to get to know them better before a more structured interview.

Ironically, the meeting at AIDS Alliance is about transportation, as the organization had recently moved locations to an office in Durham that is further away than before. At the support

group earlier that week, members of the group had expressed frustration and dismay about the new location, lamenting of how inaccessible the office currently is. From them, I learned that there is a bus stop right outside of the office, but Bus 11 only runs at 6, 7, and 8 AM and 3, 4, and 5 PM. These times are already unreasonably early, and to complicate the situation, AIDS Alliance opens at 9 AM, which places strict restrictions on who can and cannot travel to the office. Furthermore, the food pantry at the organization is only open for a few hours around noon, further preventing clients from meeting their needs.

Another bus route through Bus 20 can take clients to the office and has more accessible route hours, but as Loretta, a member of the support group told in exasperation, the bus stop for Bus 20 is more than nine blocks from the location. A week before, she had taken Bus 20 and was not aware of the distance, and being elderly, her legs became swollen from the walk. While AIDS Alliance targets their services to those with HIV/AIDS who are the most disadvantaged, the very same clients with medical conditions and disabilities, of maturing age and few resources, now do not have the means to travel to the office to access services. Understandably, this is a very real and concerning problem for the community, and people had been invited to the meeting at the Alliance to voice their concerns.

When I arrive at the library, Rhonda emerges looking relieved and happy.

“No more tears, you hear?” Irene tells Rhonda as she opens the car door.

Rhonda smiles and nods, and we set out for AIDS Alliance. As we drive, we travel through narrow, rough and crumbling streets that eventually open up into bigger highways. It is difficult to imagine a bus maneuvering through the neighborhoods when the roads are already tough to navigate in my mid-sized vehicle. After ten minutes of driving, we realize that we are inevitably going to be late to the meeting. The new location of Alliance is, indeed, far away from

the population the organization serves, and Rhonda and Irene begin to express their concern for the distance and the bus system. They are eager to voice their opinions at the meeting and to make their voices heard. In my mind, I think about how contradictory it is to have a meeting about the inaccessibility of the office at the very office itself, at a time in the afternoon when Bus 15 does not even run. I wonder who will show up, for it will undoubtedly be a small percentage of the organization's clients, those who are somehow able to use their connections to find rides.

After another ten minutes of driving, we finally pull into an upscale building complex that houses many offices. The complex looks like one that would house dental offices, insurance companies, and other small businesses, which AIDS Alliance's clients most likely struggle to access in their daily lives as well. When Irene, Rhonda, and I walk in, about twenty people are sitting in a circle in the waiting area of the office, as the meeting had already commenced.

One attendee, Margaret, hands a stack of letters to Julie, the person in charge of the Durham office of AIDS Alliance, saying "Here are the complaints from Alliance members of the new location." She reiterates how everyone serviced at the Alliance doesn't drive and begins to speak of the inconvenience of the bus hours, the defunct phone lines, and the inaccessible food pantry hours.

After listening to the community concerns, Julie is sympathetic, revealing that she is "deeply disturbed." Julie continues, "I'm glad you guys are here because it gives you an internal perspective. I'm told by my board about what we're allowed to say, and I don't want to air our dirty laundry, but you guys need to hear the truth." As she speaks, her expression changes from empathy to indignation as she highlights the financial constraints placed on the Alliance by the state. "We're facing a downsize that the state is forcing us to do. The state is telling me I have to

cut positions, and instead of laying people off, I am trying to shift case managers to the health department.”

As Julie speaks, those in the circle nod and murmur in understanding. One community member chimed in, “So that’s going to be lacking somewhere.”

Julie shakes her head. “Not according to the state. The state evaluation said that they are paying us too much for not doing enough services. Meanwhile, we have people losing jobs, rent going unpaid, the food bank being overloaded because food stamps are running out. Our governor doesn’t like nonprofits. It’s politics.”

Irene expresses in disbelief, “So there will be more crime...,” trailing off as the circle once again murmurs in agreement.

Julie replies, “We understand your frustrations with this new office, but this shows the challenges that we face too. Those that don’t deal directly with clients don’t understand what we do and the impact we have. The state stopped paying us because of the downsizing and the government shutdown. As a non-profit, we pay the bills to the state, and then we should be reimbursed. But they have backed up the reimbursements. Alliance has a reserve to run for three months, but after that, we can’t do anything. People don’t understand and have come here mad and sad, and we can’t help them because the state hasn’t paid us. So finally we directly went to a state representative and said we’re going to shut down for 60 days until we’re paid. The state got scared by the Feds for not paying us because the government shutdown wasn’t supposed to affect public health. That’s how we got \$130,000 back. And that’s just what they owed us.”

From Julie’s view, the Alliance won the first battle with the state and can focus on its clients once again, at least before the next issues inevitably arise. Julie proceeds to describe how because the previous grant for the office expired, the organization has run into problems with

funding from the state, and they now rely on donations. Due to these financial constraints, the transition to the new location has not been as smooth as they had hoped, causing people to lose access to their services. She issues a few promises, saying that the phone lines will work again soon, the Alliance office will change the operating hours of the food pantry, the disabled can have the option of having their food delivered, and the organization will possibly issue vouchers for Food Lion.

Irene speaks up next, still concerned about the unreliable services that had recently disrupted so many lives, “We can sit here and talk about it all day, but how do we take it to the next level? It’s not fair for us.”

After looking at Irene thoughtfully, Julie replies, “Our voice can continue to be heard at the quarterly meetings. The door is always open here.” After the meeting wraps up with a round of applause, people negotiate rides with each other, and I drive Irene and Rhonda home.

The scene at the AIDS Alliance community meeting raises several important issues about the role of national ideals of neoliberalism, which control people through healthcare restrictions that shift responsibility to the individual. From the funding problems to the miscommunication and confusion that surface in the community, lives are governed through political power that operate at both the national and state levels, which can oftentimes conflict and have tumultuous effects on local organizations and people. From this fieldwork story, I hope to illuminate how deeply these incongruities can affect society and how they can have real consequences for those who are often marginalized.

The exchanges I observed at the meeting also increased my awareness of the discontinuities at the local level of my fieldsite. My access to a car has constantly reminded me of the privilege I have as a Duke student. Driving around town, I can see the stark physical

contrast between Duke and Durham. While Duke and the gentrified region around the university boasts large brick buildings and green manicured lawns, the other parts of Durham are not as well kept, overcrowded with old, run-down houses. The Duke bubble is real, and the Duke-Durham relationship, both its continuities and the discontinuities, affect the health and status of HIV-patients whether students realize it or not. Duke provides a wealth of resources in terms of providing money, hospitals, and even knowledge to the town, but these resources come with certain restrictions and are not always distributed evenly. Furthermore, the university was built on tobacco money, and this history of tobacco capitalism in the city has also distorted the composition of who is affected by HIV/AIDS in Durham. I will also take time to explore how these conditions have shaped the participants that I interviewed.

Policies can concretize inequality, but as Julie demonstrated in her last comment about what can be done, people can also express themselves when they are discontent with the structures that surround them. Whether they concerned about the neglect of the state or the stigma that society directs onto an HIV-positive person, individuals have the power to create different representations of reality by using their voice, which is also what this ethnography is concerned with. I will show later in Chapters 3 and 4 how discourse can achieve specific means through the ways in which people utilize their voice and refuse to be silent.

### **Conflict and Confusion at the Intersection of Nation and State**

Producing exclusionary healthcare outcomes, national narratives of neoliberalism have extensive implications for the health of residents in more nuanced spaces such as North Carolina and Durham. Neoliberal ideals affect funding for state and local programs, the laws surrounding



diagnoses, and perceptions of those living with HIV/AIDS, and ultimately, they lead to the perpetuation of stigma by creating arbitrary and uneven social rules of silence and disclosure.

Through the transformation of health into a privatized commodity, neoliberalism has created barriers to funding, making government provisioning for resources even more difficult to obtain. Instead of equal healthcare for all, opportunities for health are only available to those with the right resources. Although the Alliance organization is already strained in having too many clients with too few case managers, the staff members also have to find the time to fill out applications for grants and funding. Their mission to care for those with HIV/AIDS is often in limbo, contingent upon government subsidies that are equally indeterminate due to the conflicts in the government. In the current political environment, the Republican party runs the state government while the Democratic party rules the national government, and because both parties have differing views on how to approach healthcare, Julie expresses frustration with the inconsistencies in funding. As Julie exasperatedly claims, “It’s politics.”

Because the American medical system involves obscenely high costs of treatment, the ability to pay can act as a barrier to care. Health insurance can alleviate the costs of doctor visits and medicines, but in the United States, insurance also acts as a commodity that must be purchased. Even if someone has the funds to acquire health insurance, out-of-pocket premiums further prevent access to treatment, and once again, deliberations of money are rife in the spaces of health. As Arlene, an employee at AIDS Alliance expressed,<sup>106</sup>

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<sup>106</sup> Arlene (employee at AIDS Alliance) in discussion with the author in November 2013.

*“The state is more concerned about finance rather than care. They look at the numbers and statistics and how much money we’re spending. Not so much as this area needs to be serviced because of need. We are not getting to whole counties. Only certain people can get the services. Like at a doctor’s office, the people who can come to you get care, but that doesn’t mean that nobody else is sick. We need to reach out to people without insurance too.”*

Arlene acknowledges that the commodification of insurance is exclusionary and creates inequalities in which those who can visit the doctor become the most visible, while those who cannot afford medical attention are overlooked in considerations of health. Because the state government is preoccupied with financial considerations rather than equal care, they neglect the poorest and the most sick, reproducing the social hierarchy.

In a recent effort to regulate healthcare and to provide national health insurance, the federal government has instated the Affordable Care Act (ACA). The law advocates for “quality, affordable health care for all Americans,” undoubtedly having an impact on the future funding and treatment of HIV/AIDS.<sup>107</sup> Considering the political tension between the state and federal governments, though, how will this national policy affect healthcare in the context of North Carolina? When I interviewed Linda from the Duke AIDS Legal Project, she referred me to the Duke AIDS Legal website in order to understand the political contention that has resulted in response to health reform.

The Affordable Care Act was originally drafted to assume that those who earn up to 138% of the state poverty level (about \$12,000) would have access to Medicaid, which is a federal-state program that funds health insurance for those who do have the income or resources to pay.<sup>108</sup> However, when the legality of the ACA went to court, the Supreme Court ruled that

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<sup>107</sup> “Read the Law,” accessed February 5, 2014, <http://www.hhs.gov/healthcare/rights/law/index.html>.

<sup>108</sup> “Health Care Reform,” accessed February 5, 2014, <http://dukeaidspolicyproject.com/health->

the federal government could require people to get insurance but could not compel states to expand Medicaid.<sup>109</sup> Thus, the North Carolina General Assembly passed legislation to opt out of Medicaid Expansion, with Governor McCrory citing a broken Medicaid system as the reason why.<sup>110</sup> The decision to refuse Medicaid expansion will be detrimental to low income and uninsured North Carolinians, who fall in between the gaps of national and state insurance. Those between 100-138% of the poverty level now have to buy their own insurance, which may be subsidized but will still be more than they can afford. On the other hand, those whose incomes are between 45%-100% of the poverty line are now, according to Linda, “left entirely in the cold,” not qualifying for Medicaid yet too poor for subsidies for private insurance.<sup>111</sup>

Linda expressed disappointment with the way in which the state government has approached the Affordable Care Act, telling me,<sup>112</sup>

*“Now, a lot of people can’t get full coverage. It’s a travesty that North Carolina hasn’t expanded its Medicaid program. It’s a purely political problem—Republicans are getting mad at Obama and are taking it out on low income people. People are falling through the cracks.”*

Political contention between the national and state governments has had an uneven effect on the population, in which the poor continue to face inequalities in all areas of life. Not only did they deny Medicaid expansion, but the North Carolina General Assembly also opted out of partnering

care-reform/.

<sup>109</sup> Ibid.

<sup>110</sup> “Governor McCrory Recommends Healthcare Implementation Strategy,” accessed February 5, 2014, <http://www.governor.state.nc.us/newsroom/press-releases/20130212/governor-mccrory-recommends-healthcare-implementation-strategy>.

<sup>111</sup> “The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid,” accessed April 3, 2014, <http://kff.org/health-reform/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>.

<sup>112</sup> Linda (lawyer at Duke AIDS Legal) in discussion with the author, October 2013.

with the federal government in the Insurance Marketplace.<sup>113</sup> In this classic movement towards deregulation, neoliberal ideals are further concretized. Attempts to provide equal access to healthcare are hindered by opposition that tout healthcare privatization, in which the responsibility of insurance falls on the consumer's ability to pay.

Not only do neoliberal policies spread an individualizing discourse in which healthcare falls on personal accountability, but people living with HIV/AIDS are also held responsible for their disease in their legal obligations if they test HIV positive.

While the national government enforces the HIPAA law in protecting health information, the North Carolina government has taken this privacy measure a step further, upholding a decree that specifically protects HIV confidentiality in public or private records.<sup>114</sup> However, this state law comes with a contradictory “statute [that also] allows disclosure in certain circumstances” such as “release to protect the public health under rules related to control measures for infectious disease” and “release made pursuant to subpoena or court order.”<sup>115</sup> Although the law emphasizes privacy as a crucial part of HIV diagnoses, this same decree comes with certain restrictions that create a complicated and confusing discourse surrounding confidentiality. These institutionalized rules tout confidentiality yet place limits on the level of privacy that can be obtained with HIV/AIDS.

Those who do test positive for HIV in North Carolina “are subject to certain legal requirements known as ‘control measures,’” such that “[b]y law, an HIV positive person shall:

- (a) refrain from sexual intercourse unless condoms are used; exercise caution when using condoms due to possible condom failure;

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<sup>113</sup> Ibid.

<sup>114</sup> Carolyn McAllaster, “Protecting the Confidentiality and Security of Sensitive Health Diagnoses like HIV in North Carolina” (manuscript prepared for health practitioners, Durham, North Carolina, June 2013).

<sup>115</sup> Ibid.

- (b) not share needles or syringes, or any other drug-related equipment, paraphernalia, or works that may be contaminated with blood through previous use;
- (c) not donate or sell blood, plasma, platelets, other blood products, semen, ova, tissues, organs, or breast milk;
- (d) have a skin test for tuberculosis;
- (e) notify future sexual intercourse partners of the infection;
- (f) if the time of initial infection is known, notify persons who have been sexual intercourse and needle partners since the date of infection; and,
- (g) if the date of initial infection is unknown, notify persons who have been sexual intercourse and needle partners for the previous year.”<sup>116</sup>

Furthermore, the law mandates that the HIV-positive person must notify the spouse of the test result but is not obligated to tell his or her current partner if unmarried.<sup>117</sup> If HIV-positive people fail to meet these requirements, then they are committing a misdemeanor and are subject to up to two years in prison.<sup>118</sup>

While other diseases are not associated with legal obligations, the state government specifically targets people living with HIV/AIDS for control. The selective criminalization of HIV/AIDS reaffirms public fear of the disease and serves to instantiate stigma, and the laws both shame and blame the individual. If the person does not comply, he or she will be considered as a law offender, an immoral individual who must be put in prison for his or her wrongdoings. Linda recognizes the contradiction with the laws that do not serve to protect those with HIV/AIDS, but rather hinder them from equal treatment. She reveals,<sup>119</sup>

*“There’s a lot of concern about that law being ineffective and not furthering public health goals, but that is our law. In my opinion, having a criminal law in the book won’t help people disclose. It’s not helpful. It stigmatizes people and puts it on their record so that for future job opportunities, employers will see it and will be less likely to hire them.”*

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<sup>116</sup> Ibid.

<sup>117</sup> Ibid.

<sup>118</sup> Ibid.

<sup>119</sup> Linda (lawyer at Duke AIDS Legal) in discussion with the author, October 2013.

The targeted prosecution of those who are living with HIV/AIDS prevents access to future opportunities, further perpetuating disease and stigma.

Moreover, the criminalization of HIV/AIDS also creates subjective measures of disclosure. What is considered necessary to “protect the public health,” and who makes these distinctions of what the law can disclose?

Irene reveals to me that she is still resentful of the public health department for neglecting to tell her about her then boyfriend’s HIV status. Rolling her eyes, Irene exclaims in exasperation,<sup>120</sup>

*“I’ll probably go to the grave blaming the health department. They flipped it on me. They knew about it and said, you need to know about the status of your partner. They sacrificed 4 lives for one—my three children and me. The law is crazy, and I don’t get it. By law, you only need to tell a partner that you’re positive if you’re married, not dating.”*

In this instance, the state health department made the decision to protect the right of privacy of Irene’s boyfriend over her and her family’s health. The convoluted stipulations of the law have created hazy differentiations of the appropriateness of confidentiality, in which disclosure becomes arbitrarily upheld by those who are least affected by the disease. Because Irene was a girlfriend and not a spouse, those in the health department had the power to choose whether to tell Irene, citing the right to her boyfriend’s confidentiality. Instead, the burden of legitimacy and proof shifts onto the individual who is most in harm’s way. In these ways, some end up suffering more than others due to the uneven statutes and application of the state law.

### **Disjointed Localities**

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<sup>120</sup> Irene (HIV-positive participant) in discussion with the author in September 2013.

Zooming in even further, I will now evaluate the state of HIV/AIDS in the context of Durham. The city embedded in a history of segregation and remains divided by race to this day, which has implications for the burden of disease. During my fieldwork, patterns of segregation emerged as I interviewed participants and attended meetings. In the support groups and community gatherings, I noticed that most attendees were African-American except for the few who conducted the meetings or who worked through Duke University Hospital. Similarly, all of my participants who were HIV-positive were African-American while those who would serve as the “public figures” in my research, such as the lawyer and nurse, were not. Thus, separations by race surfaced between those who were receiving care and those who had the abilities to provide care.

What do these patterns tell us about health, stigma, and power in Durham? While stigma by race can layer upon the stigma of HIV/AIDS to intersect with identity and experience, in the context of the city and in my group of participants, I will focus more specifically on how economic power has produced this visible segregation and has resulted in an unequal burden of health. By evaluating the history of Durham, I will consider how inequalities created by capitalism have affected the demographics of my encounters in the realm of HIV/AIDS.

With landmarks in Durham termed the “American Tobacco District” and the “American Tobacco Trail,” it may come to no surprise that tobacco has played a formative role in Durham’s history. While the tobacco industry in the United States has roots dating back to the 1800s, tobacco did not become a major cash crop for the Carolinas until the early 20<sup>th</sup> century, in which farmers realized that they could cultivate and control the quality of tobacco better with the lighter

soils of the area.<sup>121</sup> After the Civil War, Durham experienced a migration of slaves that coincided with the development of tobacco-manufacturing plants and the subsequent increased availability of jobs.<sup>122</sup> However, conditions of overcrowding soon led to white flight out of the center of city and into suburbs at the edges although white families still remained in control of a large amount of land.<sup>123</sup> They rented the land to African American families, who provided the manual labor for the tobacco plants.<sup>124</sup> To retain control, the white tobacco elite devised ways to keeping the labor surplus high and the wages low through city zoning techniques and the institutionalization of new laws.<sup>125</sup> They sought to create black dependence on white landowners through credit and debt, seeking to solidify the inequalities in wealth for their own benefit.<sup>126</sup>

James B. Duke became a powerful figure in the tobacco industry when he obtained control of a patent on a new, highly efficient cigarette rolling machine, effectively squeezing out competition to monopolize the market.<sup>127</sup> Through his innovative approaches to industrial organization and marketing, Duke was able to secure his control over the industry, and by 1911, “Duke achieved a tobacco empire that controlled 90% of domestic sales and more than 60% worldwide [...]”<sup>128</sup> Durham became the headquarters of Duke’s tobacco enterprise, and Duke’s extensive influence in the market allowed him to exert great command over the prices of tobacco at auctions. Because “tobacco buyers often underpaid black farmers in comparison to white

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<sup>121</sup> Peter Benson, *Tobacco Capitalism: Growers, Migrant Workers, and the Changing Face of a Global Industry* (New Jersey: Princeton University Press, 2012).

<sup>122</sup> Ibid.

<sup>123</sup> Ibid.

<sup>124</sup> Ibid.

<sup>125</sup> Ibid.

<sup>126</sup> Ibid.

<sup>127</sup> Ibid.

<sup>128</sup> Ibid., 73.



farmers, which was permitted by collusion among buyers and warehouse personnel,” black farmers oftentimes faced unfair treatment and lower economic gains.<sup>129</sup>

As shown, “the social world of the tobacco town and the surrounding countryside was completely infused with racial meanings and the tobacco business built on basic divisions” since early in time.<sup>130</sup> Durham’s history of tobacco capitalism and the manipulations that took place to ensure white elite control created a city that was segregated by race and wealth, conditions that have been further reinforced in times of neoliberalism. In the 1970s, structural adjustment policies caused tobacco-manufacturing companies among other industries to outsource their production to other parts of the world, causing major layoffs.<sup>131</sup> These job cuts primarily affected African Americans, and combined with “the war on welfare, failures to raise the minimum wage, the contraction of low income housing, the decomposition of residential and industrial zones around cities [...], and the depredation of rural and urban tax bases for public schools—all of these [...] historical factors [...] have worsened living standards and made life precarious in many communities since the 1980s and increased dependence on social assistance.”<sup>132</sup> This deeply entrenched past is the “the complex cause of why black people came to make up a substantial proportion of welfare roles,” and why we might see HIV/AIDS primarily affecting the African American community in Durham.<sup>133</sup>

This storied past shows how structural conditions have led to unequal economic opportunities for poor African Americans, who are constantly subjected to policies and laws that make access to resources uncertain. For example, Irene called me one day to tell me that her

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<sup>129</sup> Ibid., 75.

<sup>130</sup> Ibid.

<sup>131</sup> Ibid., 227.

<sup>132</sup> Ibid.

<sup>133</sup> Ibid.

phone would not be working for a month because she had to use her communication funds to buy medicine instead. The support group I attended also ended since Irene could not obtain funding for the regular meetings and could no longer afford to sustain the group by herself. Furthermore due to the past white flight from inner cities to the suburbs, African Americans faced barriers to employment since the government failed to provide the means to travel outside the city limits. The meeting at AIDS Alliance shows that the politics of public transportation remains a contentious issue to this day, for those affected by HIV/AIDS, who are often the most vulnerable, are not afforded equal access and still face obstacles to healthcare.

Pervasive neoliberal ideals have converged with Durham's history in ways that have made life difficult for those who are affected by disease, emerging as the city's current reality. After taking away their opportunities for a comfortable livelihood, the government and the wealthy then deny the poor the funds to remain healthy or to seek treatment. Instead, they are held responsible for their poverty and blamed for their infection, which perpetuates the cycle of disease in certain races and classes. For example, the CDC cites that "African Americans are the racial/ethnic group most affected by HIV," with the "rate of new HIV infection in African Americans [...] 8 times that of whites based on population size."<sup>134</sup> The CDC also found in a study that "HIV prevalence rates in urban poverty areas [are] inversely related to socioeconomic status (SES)—the lower the SES, the greater the HIV prevalence rate."<sup>135</sup>

Because the burden of HIV/AIDS falls along such racial and class lines, who gets the disease and who does not also affects the perceptions and negotiations of stigma. In conditions of

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<sup>134</sup> "HIV Among African Americans," accessed April 2, 2014, <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>.

<sup>135</sup> "Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?," accessed April 2, 2014, <http://www.cdc.gov/hiv/risk/other/poverty.html>.

privatization and individualism, my participants have responded in ways that seek to alter the negative production of the disease through reasserting their voices. By having a say in government policies and at meetings, they can gain funds for the healthcare that has been denied to them along boundaries of race and class. Organizations such as the Duke AIDS Legal Project can help those affected by HIV/AIDS secure resources through prosecuting cases of stigma and discrimination. During my time with Irene, she revealed that she was engaging in a legal battle with the help of Duke AIDS Legal against a dentist's office, who refused to see her because of her disease and exposed her status to everyone in the room. By manipulating institutionalized laws and turning disclosure onto itself, Irene waits for her time in court when she can testify about her experiences. Through the power of discourse, she fights for a more equitable manner of living, one in which stigma may no longer be a negative factor in her life.

## **Chapter 3: The Secret is the Power: The Production of Isolation and the Expectations to Overcome**

### **Getting to Know Irene**

As my first participant, Irene is everything a novice, thesis-writing student could hope for. She speaks freely and openly and is introspective as much as she is extroverted. Even though she has struggled with her HIV diagnosis in the past, she lives in the present and looks forward to the future with a contagious spirit. Conveying confidence and an appreciation for life, Irene has led me to question my own reality through her insight, and she has been an influential force in the direction of my fieldwork.

The first time I met Irene had been at the 5K race. The second time, we decided to meet in a more intimate setting, a place where the background noise would not come from people crossing a finish line, but from soap stars on the television. We would meet at Irene's house. When she called me to organize the interview, she seemed hesitant when I asked her where she would like to have the interview. After a brief pause, she suggested her house with a note of diffidence in her voice. I agreed right away, but at the same time, I wondered why she seemed nervous. Was Irene afraid that I would be uncomfortable in her house because of her HIV status? Was she hesitant because the possibility of stigma lingers in her thoughts?

A few afternoons later, I pull up to Irene's driveway and begin to feel a sense of anxiety. Irene is the first person I am interviewing for my fieldwork, and because I do not know what to expect, I am worried about how our meeting will go. When I approach the door, I notice that two men are sitting outside talking quietly. They turn to look at me and I dutifully introduce myself. Concerned that my car might be blocking their driveway, I then ask if I should move my car.

Tim, who I later learn to be Irene's husband, smiles at me and jokingly tells me that Irene does not get a lot of visitors.

At that moment, Irene emerges from inside the house and laughs at Tim's comment. She proceeds to usher me into the house with warm welcomes, introducing me to her family as each person files into the living room to greet me. I am taken aback by the family's warmth and openness. They remind me of home, and in those few initial moments, any anxiety I had dissipates. I settle down on the couch with ease, now eager to engage in conversation with Irene.

As we begin to talk, I share my side of the story: my roots, my interests, and my research project. Irene inquisitively asks about my family and my life as a student, telling me that she likes to ask many questions because it is better to ask than to wonder and assume. When she is satisfied with my answers, she naturally turns the conversation towards her own experiences. Irene is not shy in the least. She dives right into her story and begins by telling me about the moment she was diagnosed in the early 1990s.

“When I first found out I was positive, it was from my second husband. He was how I contracted it. He genuinely didn't understand that he had HIV—he told me it was cirrhosis of the liver. Something told me to get tested, and when I did, I was treated very coldly.”

Irene becomes reflective, and after a pause, she smiles at me and continues her story.

“It was a big shock to me. I didn't want to tell anyone at first, but I told my children because I didn't want them to touch my blood if I got cut. I worked in the food service, and I was constantly worried about getting cut and infecting others. I had a disease that I couldn't talk about or tell anyone about. I didn't know how people would respond to my disease. People joked about it, about contracting it. They didn't know it hurt.”

Looking back, I wonder whether Irene had been wary about having our meeting take place at her house because of the “fear of contagion,” as Dr. Sanders has described. HIV/AIDS has been rooted in a fear of infection since the disease’s conception, informing the stigma experienced by people living with HIV/AIDS to this day. The stigma of HIV/AIDS, in which the disease is seen to define the person, propagates the notion that those living with the disease are somehow different from the rest, reduced from a “whole” person to a “discounted” one as Goffman suggests.<sup>136</sup>

The healthy are afraid of those infected by HIV/AIDS due to the potential of contracting the disease through bodily fluids, and when Irene emphasizes her personal fear of infecting others, she expresses a sense of responsibility over her disease. The stigma creates the belief that the blood flowing through Irene’s veins is tainted, and likewise, Irene expresses that she felt the same way when she was first diagnosed. Not only do people fear Irene for her disease, but Irene had feared infecting people, believing that HIV/AIDS is an unclean, personal disease in which she is held accountable for any consequences. She felt as if she could not confide in anyone, as if she was isolated from the rest due to a biological difference. Others did not consider the real consequences that HIV had on individuals, carelessly joking about the disease and using words to emotionally hurt those living with the disease. In these ways, the discourse created by those who are healthy leads to less visible forms of discourse by those affected, which can aid in propagating stigma. Without needing me to prompt her, Irene becomes even more reflexive and steadily continues to tell me about her experiences.

“HIV wasn’t a physical disease as much as a mental one. I had to hide it for so many years. When I got my medicine, they had HIV labels on the top. I would peel them off to prevent

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<sup>136</sup> Goffman, *Stigma*.

anyone from finding out. I would hide it because I didn't want anyone to know. When you went to get healthcare, there was only one door you could go in, and everyone would know you were HIV positive. This door was next to the early detection door, and I would try to sneak through the other one in which your status was uncertain. I hated it. I hated it with a passion. I even hated to sit outside in the hospital even though I liked the sun. I was scared I would see someone I knew. I dealt with this for years.”

The societal fear of HIV/AIDS led to personal fear of being ousted for her disease, and Irene felt the need to keep her diagnosis a secret. Although I already begin to feel saddened by these negative experiences, Irene has even more to share. She further recounts her struggles to keep the diagnosis to herself and expresses sentiments of isolation.

“My first doctor at Duke was not good. He read my chart and came back with a face mask and coat on. I sat there thinking, oh my gosh, I must be *dirty*. I was so hurt, but who was I going to tell. There was nobody to tell. Nobody knew I was positive.”

Besides her children, who were too young to understand the magnitude in which HIV changed her life, Irene felt secluded from the rest of the world. The stigma associated with HIV/AIDS had left her with the belief that she could not tell anyone about her diagnosis, for they would be afraid of her and would make judgments about her lifestyle choices.

“You can always tell someone you got diabetes. You can tell them you have cancer. But you can't tell them you have HIV because you just can't do that—you can't call in sick with HIV. Society should accept you with who you are instead of your lifestyle, but they pre-judge you depending on how you dress, look, and what church you go to. People don't care how high my CD4 count is, yet it's easier to talk about having HPV because of the fear. I always tell

people that you can make me sick quicker than I can kill you. This is the stigma behind HIV. If you have a cold, I can catch it and get pneumonia. It's not like I'm trying to kill you."

For Irene, HIV/AIDS differs from other diseases due to the stigma associated with it. Morality judgments and societal fear burden those living with HIV/AIDS, leading to internal conflicts of worthiness versus unworthiness, disclosure versus nondisclosure.

Switching to the present tense, Irene suddenly asks herself, "Do I still deal with stigma?" After a long pause, she confides in me, "In my mind, I do. I think stigma isn't as negative as it once was, but it's still there. We can't erase it, but the degree of stigma changes. I'm not as fearful as I used to be, but it's still there. Even though this was almost twenty years ago, the same things are still going on. When I went to the dentist, I was denied services. They disclosed my HIV status in the lobby in front of everyone. It was like a slap in the face—here it is in 2012 and we still have stigma."

Similar to what Dr. Sanders expressed, Irene reveals that although stigma can be evaluated on a scale, she does not believe in an end to stigma. Instead, she and others see stigma as an undeniable part of the HIV experience. While Irene's outlook may be bleak due to the many obstacles she has faced, this sense of permanence is problematic in that it shifts the site of intervention from the institutions and ideologies that propagate the stigma to the individual that is living with stigma. Instead of aiming to eradicate the negative perceptions on the part of society, we focus on merely improving the outcomes those affected, further entrenching the stigma. Consequently, the bulk of research conducted by scientists such as Dr. Sanders focus on methods to alleviate stigma and develop self-esteem in HIV-positive patients. These studies stress the importance of confidentiality and silence about the diagnosis, which become widely perceived as the most dependable method in avoiding stigma. Because stigma is viewed to be



supposedly constant, sentiments of loneliness and seclusion are imagined to be a natural part of living with HIV/AIDS that must be overcome. Irene initially feels as if she cannot tell anyone when she is diagnosed due to perceptions of an undeniable stigma, and accordingly, Irene goes on to describe a personal journey of acceptance to me.

“I had to learn to accept it. I had to love myself and find out who I was. I’m somebody’s mother, daughter, grandmother. I’m not HIV. Once I came to grips with it, I didn’t want anyone to experience what I experienced. I turned my life around, and I didn’t want anyone to go through what I went through.”

Why does Irene believe that she is the one who needs to change, the one who has the responsibility of turning her life around when negative societal stigma produced the feelings of isolation in the first place? Why is the emphasis on the individual to overcome when experience is informed by friends, family, politicians, lawyers, scientists, and ideologies? Everything in the world is connected, yet the emphasis here is on the individual to conquer an environment that institutional powers have produced and society has perpetuated.

Neoliberalism emphasizes individual bodily control, and its political and legal productions have shaped discourse, stigma, and the lived experiences of HIV/AIDS. While people may often overlook the structural mechanisms in which stigma is created, society frequently isolates HIV/AIDS to a single person in which the individual is both blamed for the diagnosis and is demanded to overcome the odds. Stigma has produced the expectations that HIV/AIDS cannot be discussed, but at the same time, these ideologies have created a narrative in which a positively diagnosed person should rise to the top through an existential journey of acceptance, comparable to the national ethos of the American Dream. I will explore these parallel neoliberal narratives further, evaluating how neoliberalism has transformed HIV/AIDS

into an individualistic disease that calls upon ideals of personal freedom and self-governance. These values inform stigma, and a discourse of both attribution and silence emerges, both ultimately having embodied consequences for those living with HIV/AIDS.

### **Neoliberal Rationalities of Bodily Control**

With the emergence of neoliberalism, policies have shifted healthcare from a public good funded by the state to a private good that an individual must have the funds to buy into. As care is no longer a responsibility of a welfare state but the responsibility of the self, the deregulation of government has subsequently installed the concept of a privatized life and, thus, a neoliberal subject. Margaret Thatcher, an influential early proponent of neoliberalism, famously declared that there is “no such thing as society, only individual men and women.”<sup>137</sup> Due to the intense emphasis on individual control, neoliberalism has dissolved the ties of one to society, instead rationalizing a person into an “autonomous, individualised, self-directing, decision-making agent.”<sup>138</sup>

In these ways, when people become sick with HIV, they are held responsible for their disease. Neoliberal modes of thinking promote the notion that an individual has made the personal choice to disregard his or her health by making unwise decisions, which is the space in which stigma arises. Instead of striving for health, those living with HIV/AIDS are assumed to have engaged in promiscuity and high-risk activities such as prostitution or drug use, which are

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<sup>137</sup> David Harvey, *A Brief History of Neoliberalism* (Oxford: Oxford University Press, 2005), 23.

<sup>138</sup> Liz Bondi, “Working the Spaces of Neoliberal Subjectivity: Psychotherapeutic Technologies, Professionalisation and Counselling,” *Antipode* 37, no. 3 (2005): 497.

moralized onto the individual. As Dr. Sanders described of the stigma, “people believe people who get it deserve it. People believe they needed to do something to get HIV.”<sup>139</sup>

Because neoliberal ideals of individualism advocate for responsibility over one’s own health, stigma has created a sense of isolation for those who do become sick in which silence is considered the most suitable option. As Harold expressed to me,<sup>140</sup>

*“People didn’t understand the disease because there was a negative stigma. So I said I would deal with this by myself—it would be easier. I never let it bother me, and I didn’t want to bother my family with it.”*

As someone who is HIV-positive, Harold was fearful of the stigma and the potential judgment by the community, feeling as if he could not disclose his status to anyone. By imagining a subject as purely autonomous, the neoliberal discourse surrounding HIV/AIDS has created a powerful stigma in which those who are living with the disease are discouraged to engage in dialogue. Words are replaced with silence. Instead, the community emphasizes confidentiality in every aspect of living with HIV/AIDS. From the tests for HIV to scientific studies, a widespread notion that confidentiality is always important because stigma is always present has taken shape, further reinforcing the social exclusion of PLWHA from the rest of the healthy population.

At an HIV Treatment Update that I attended, Dr. presented his recent study of HIV/AIDS, one that looked at coping mechanisms and the effectiveness of a stigma reduction method. Once again, instead of examining the broader social context in which stigma affects individuals, the study isolates stigma to single bodies, stressing “intervention” for the participants. Instead of challenging the idea of stigma, the research is founded upon the premise

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<sup>139</sup> Dr. Sanders (nurse practitioner and researcher) in discussion with the author in November 2013.

<sup>140</sup> Harold (HIV-positive participant) in discussion with the author in October 2013.

that stigma is a fundamental, uniform part of the experience of HIV/AIDS. Separated from others in society, PLWHA are held to be constantly at risk of having their secrets disclosed. At many points in his presentation, Dr. Sanders emphasized how the study did not accidentally disclose any research subject's HIV status during the research. His urgent stress on confidentiality sparked my interest, and when I had the chance to speak to him, I asked him why he believed confidentiality to be imperative. He told me,<sup>141</sup>

*“Every individual has the autonomous right to share their personal health information. In HIV research, it is absolutely important to protect them. We had to deliver an intervention that was safe and feasible.”*

Invoking the autonomous self, Dr. Sanders reveals how the idea of confidentiality is enmeshed in neoliberal productions of individuality and choice.

Just as those who do the stigmatizing embody neoliberalism, those living with HIV/AIDS continue to preserve these neoliberal views by regarding their bodies as isolated ones in which they cannot share their diagnoses. While I recognize that those living with HIV/AIDS do experience negative judgments and discrimination and may desire to keep their information confidential, I argue that confidentiality is a problematic issue, a mechanism of neoliberal governance that reinforces stigma. When I asked my participants why they believe HIV testing is anonymous, they respond to me in the same ritualized manner: for purposes of confidentiality. With these perverse notions of confidentiality that have formed in response to stigma, though, representation has become skewed. The discourse that has become dominant about HIV/AIDS only serves to promote anxiety and attribute blame, and the diverse experiences of those affected by stigma remain unaccounted for. Silence can serve the status quo, as refusal to talk about certain issues permits others to control the dialogue that takes shape.

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<sup>141</sup> Dr. Sanders (nurse practitioner and researcher) in discussion with the author in November 2013.

Besides emphasizing personal decisions to remain healthy, neoliberalism has also created expectations of becoming healthy if one does become sick. Not only does the burden of health lie on an individual, but individuals must also overcome the disease to become a good neoliberal subject. In the previous quote by Dr. Sanders, he reasons that people are “autonomous,” but he also appeals to the “right” of the individual to make decisions. These rights are entrenched in calls for American freedom that neoliberalism is fueled by. Having analyzed the importance of sovereignty in the expression of neoliberalism, I will explore the other fundamental theme of freedom in the next section.

### **Understanding HIV/AIDS through the American Dream: Narratives of the Neoliberal Body**

James Truslow Adams first coined the phrase the “American dream” in his novel *The Epic of America*, in which he imagines a “land in which life should be better and richer and fuller for every man, with opportunity for each according to his ability or achievement.”<sup>142</sup> In his idealistic views, Adams touts free will and the ability of the individual to overcome inequality, for “there is nothing whatever in a fortune merely in itself or in a man merely in himself. It all depends on what is made of each.”<sup>143</sup> Although a man may face obstacles due to his social class or circumstances of birth, drive and determination alone can help him achieve prosperity. This conception of the American dream is founded upon notions of individual freedom and the ability to exercise personal willpower.

Similarly, Harvey describes how in neoliberal policies, the “assumption that individual freedoms are guaranteed by freedom of the market and of trade is a cardinal feature of neoliberal

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<sup>142</sup> Adams, James T, *The Epic of America* (Boston: Little, Brown, and Company, 1931), 404.

<sup>143</sup> Ibid. 411.

thinking.”<sup>144</sup> By invoking these seductive, historically ingrained ideals of freedom, neoliberalism has become a powerful force in daily life. Both the American dream and neoliberalism are enmeshed in concepts of freedom and emphasize the ability to overcome obstacles with personal will and fortitude. In the context of HIV/AIDS, those living with the disease must strive to regain health even in the adverse environment created by stigma, for success would permit those affected to become good neoliberal subjects once more. Thus, the concept of “self-help” comes to pervade medicine in the United States, and those who are sick have to personally surmount their diseases.

As Martin shows, the American preoccupation with flexible bodies is also enmeshed in a long-established “tradition of thinking and practices [...] that] runs deep in American culture, that of self-help and improvement.”<sup>145</sup> This “pull-oneself-up-by-the-bootstrap tradition” frequently arose as a theme of reference in her fieldwork, in workplace training conventions and in her discussions with participants.<sup>146</sup> In this rationale of self-improvement, people can become more flexible by experimenting with one’s abilities and adjusting oneself as necessary.<sup>147</sup> Likewise in my fieldsite, I noticed that my participants expressed notions of self-responsibility to overcome struggles and to adapt to situations, which arise in the context of these national ideals of freedom and accountability.

Accordingly, Irene was not the only one who revealed a personal journey of acceptance and defeat of her disease to me. Although experiences are always variable, I thought it was

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<sup>144</sup> Harvey, *A Brief History of Neoliberalism*, 7.

<sup>145</sup> Martin, *Flexible Bodies*, 217.

<sup>146</sup> Ibid.

<sup>147</sup> Ibid.

curious that other participants shared a similar theme of recognition of their diagnoses. Rhonda pronounced proudly,<sup>148</sup>

*“HIV has given me a new life. I learned to accept me just the way I am. I let go of my low self-esteem and learned that I am someone no matter what. You. Are. Some. Body. Remember that.”*

Rhonda has come to accept her disease as Irene had, and instead of questioning why society has caused her to feel the need to come to terms with a biological difference, she reinstates the locus of responsibility on herself.

Media has power in ideas of the American dream in the context of HIV/AIDS, and the narrative of overcoming the odds and becoming satisfied with the self can also be visualized in informational brochures, which is frequently distributed to HIV/AIDS patients.<sup>149</sup> In a comic book form of a guide created by Atripla, a company that produces medications for HIV-1, Cyro is depicted as a prototypical patient coming to terms with his disease (Panels 1-3). The cartoon voiceover is told through the first-person perspective, highlighting the autonomous self once more. When Cyro receives his diagnosis, he does not know how to accept the disease and engages in dangerous behavior instead. He blames himself, saying “I know I keep messin’ up, but what’s the point in changing things now? But I soon hit rock bottom and I realized that I needed to make a change” (Panel 1). *He* needs to make the change, not others. The guide does not explain why Cyro believes his “life was over,” instead focusing on the negative experience of the disease as felt by the individual (Panel 1). The stigma that society produces is never mentioned throughout the book, as the stigma is assumed to be inherently present and uniformly detrimental to HIV patients.

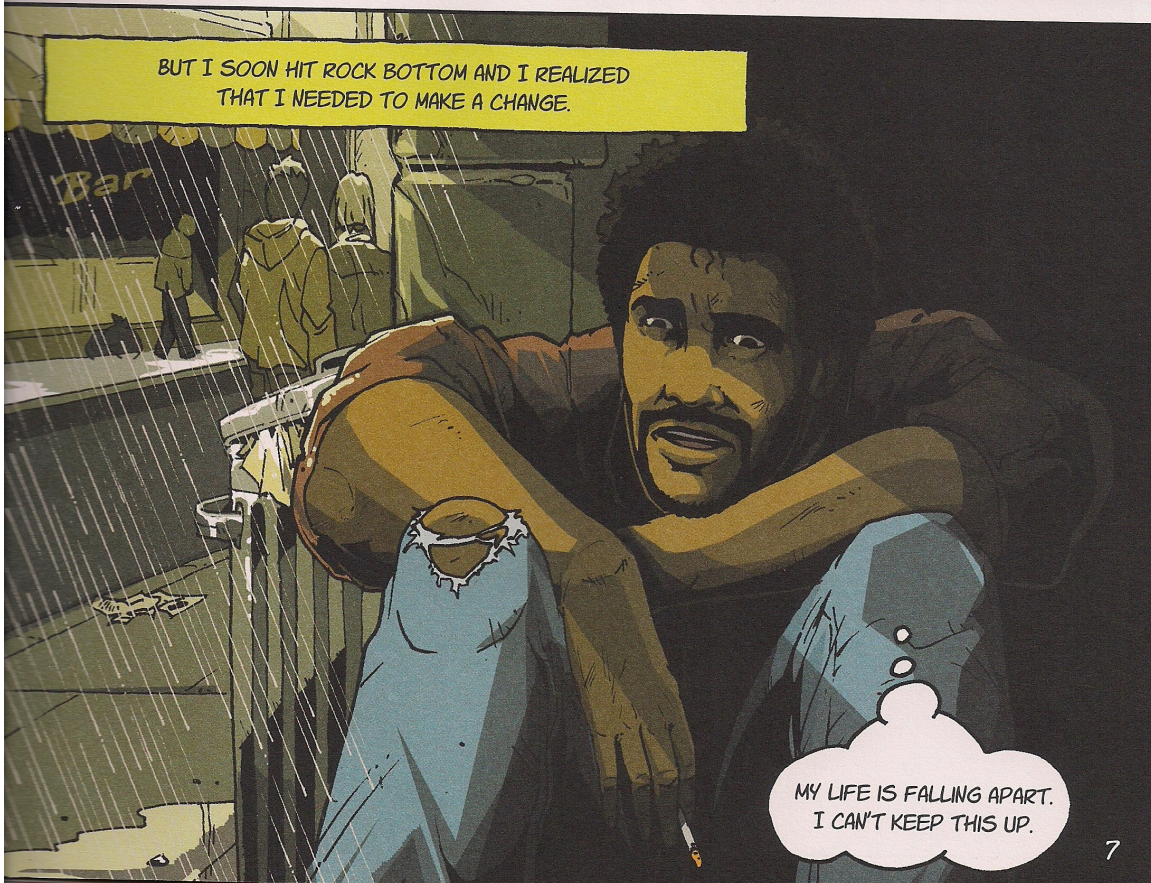
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<sup>148</sup> Rhonda (HIV-positive participant) in discussion with the author in December 2013.

<sup>149</sup> Atripla Peer Advocate Network, “Making Changes: Cyrano’s Journey with HIV.”



Panel 1





Panel 2





Panel 3



Eventually, Cyro comes to acknowledge his disease and seeks help, saying “I finally started taking steps to deal with my HIV” (Panel 2). When he finally summons the courage to tell his friends and family, they are shown to be supportive, and according to Cyro, “accepting my HIV status gave me a new perspective on life” (Panel 3). This last quote mirrors that of Rhonda’s in which she attributes the disease to giving her a new outlook on life, one that seems to be more positive than before her diagnosis. The HIV-positive individual has overcome the social barriers of judgment and shame, and in this rebirth, they have grown to accept themselves as individuals.

In the circulating stories of those who have HIV/AIDS, people are perceived to have sole autonomy, so contracting the disease is a consequence of individual behavior. Concurrently, these discourses also emphasize the individual’s freedom to overcome the stigma that fundamentally accompanies the disease. This weight on rights, however, comes with certain consequences. As Harvey insightfully asserts, “by focusing on those rights rather than on the creation or recreation of substantive and open democratic governance structures, the opposition cultivates methods that cannot escape the neoliberal frame. Neoliberal concern for the individual trumps any social democratic concern for equality, democracy, and social solidarities.”<sup>150</sup> Neoliberalism emphasizes the American dream, and concurrently, the fulfillment of the American dream reproduces neoliberal values. By perpetuating these narratives of silence and acceptance, neoliberal notions of bodily control are reinforced, and societal productions of neoliberalism such as stigma may be consumed without questioning. Consequently, our perspectives change. We become more reluctant to discuss the social conditions that create and maintain stigma, and instead, we focus on strategies that will prevent stigma on an individual level.

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<sup>150</sup> Harvey, *A Brief History of Neoliberalism*, 176.

## Secrets and Disclosure

Neoliberalism invents a paradox in which one is expected to remain confidential about a diagnosis yet must concurrently overcome the disease. So where do the spaces for agency emerge then? How can one resist the structures in place?

One day when I was speaking to Irene, she suddenly turns to her friend Connie and asks, “If you were positive and wanted to disclose to your partner, would you start with telling the partner about HIV?”

After a moment of thought, Connie responds, “Well, I can’t perceive someone as a partner without telling them. The secret is the power, not the knowledge. I’m not inviting anyone home who isn’t accepting of who I am, who my friends are, how I live. I’m not giving anyone power by not telling them.”

*The secret is the power, not the knowledge.* This quote is insightful and powerful at the same time. Instead of viewing HIV/AIDS as a disease that one has to personally accept, Connie reveals that acceptance lies with society. In this role reversal of neoliberal effects, the site of intervention is not centered on the autonomous self, but rather, society as a whole must be considered. In the next chapter, I will explore what happens when a neoliberal subject no longer consents to be a subject, and no longer consents to remain silent.



## Chapter 4: Surviving and Enduring, when Silence is Not Enough

### Getting to Know Lisa

Lisa is a new face in the support group. Sporting a velveteen tracksuit and two youthful pigtails, she takes the seat directly across from me. A three-year-old girl wiggles next to her, trying to find comfort in the too large plastic chair. Every time I look in her direction, the little girl smiles sweetly at me and waves. Lisa has attended the group before, but because she has had family obligations, she had not been able to attend the last few meetings that I had been present for. I am a new face to her too.

The speaker for today's support group begins to discuss the topic of the day. "What is domestic violence?" Ms. Jeanine asks.

After a brief moment of hesitation, I hear Lisa speak for the first time. She responds, "Domestic violence is physical or mental abuse. Someone will try to tell you that you can't do this. You're not good enough for this. You're not worth it." Her voice is loud and assertive, and her face becomes unsettled with indignation with each sentence. Her words and expression betray a personal history of being told of her failures, inferiority, and mediocrity. For the rest of the time, Lisa becomes outspoken about how she will not let anyone take advantage of her or put her down.

Ms. Jeanine continues to lead the group in discussing domestic violence as well as ways to love oneself, and the support group wraps up with a moment of reflection for the future. Ms. Jeanine challenges everyone to apply a positive outlook to everyday life. "Compliment your sisters. Tell them you like their blouse. You might not know her or what she's going through, and she may not have been complimented before. But you just might be making her day better."

Everyone in the group claps as the session ends. As people begin to leave, Irene introduces me to Lisa and asks me to drive her home. When we descend the stairs, I help to carry the stroller. Walking down the stairs for Lisa is a slow, painful process because of her arthritis, and she struggles to help the little girl down the stairs in addition to her own body. When we are in the car, Lisa and I begin to discuss how I became involved with the support group. Lisa asks me how I know Irene, and I explain that I met her at the HIV/AIDS awareness race the previous month. I begin to tell her about my research project about the lived experiences of HIV/AIDS and how Irene has been a big help.

Unexpectedly, Lisa replies, “I’m HIV-positive too. I was raped when I was younger, and it was a hard time. I couldn’t walk. I couldn’t talk. I had to go through therapy, so now I can talk about it.” I am taken aback by her nonchalant attitude as she tells me about her experiences. Although I have only known her for thirty minutes, she does not hesitate to share these personal moments with me.

That weekend, I meet with Lisa again. I pick her up from downtown, where she has been for hours to train to become an HIV peer specialist. She walks slowly, her arthritis acting up again. In the car, she explains to me that she had just finished the last training session, the one that tested whether participants had learned anything, and surprisingly, everyone remembered their material. Lisa continues to tell me about how she had been a licensed practical nurse for ten years and cared for patients with Parkinson’s, which was work that she really enjoyed. She became close with one patient whom she assisted for many years, and when her patient died, Lisa became very upset and began to drink. Around the same time, her daughter was murdered. “I’m not saying that this is an excuse to my drinking, but it happened,” she says, betraying little expression on her face. At that point, her life began to spiral out of control, and she lost her LPN

license since she did not get have the motivation to get it renewed. In addition to HIV and arthritis, she had to move away from her family to receive cheaper healthcare for cancer. Despite these hardships, Lisa does not strike me as timid or troubled at first glance. She speaks confidently and is not reserved about her past.

When I sit down to interview her in her apartment, I ask her questions more focused on her experiences living with HIV. As it turned out, this was one of the more difficult interviews I conducted, not because Lisa was not willing to talk, but because I seemed to be asking all the wrong questions.

Lisa begins the conversation by reminding me about the way she contracted HIV. “I didn’t get HIV from being promiscuous or doing drugs. I was raped, and it changed my whole world. I didn’t forget but I learned how to forgive.”

She tells me about her relationships, and when I ask about her experiences of telling other people of her status, she seems to be offended by the question. “I don’t think you understand. I was in a relationship with someone for 30 years, but I never wanted to be married because I wanted a career. He knew about the rape and that I was HIV-positive, and he accepted it. We are still best friends.” She looks at me with annoyance as she qualifies her past relationship.

Deciding to be more cautious, I try to talk about HIV from another perspective, asking whether she has ever had a problem with someone accidentally disclosing her status. Once again, she becomes indignant. “I’ve never had a problem with disclosure. Medically, I’m going to let someone know about me being HIV-positive because I could be bleeding. If they have a problem with it, it’s on them. I would tell whoever I want to know, I’m not ashamed of it, but some people I won’t tell.”

Earlier in the interview, Lisa had expressed to me that she does think there is stigma associated with HIV due to ignorance. But with the direction of the conversation, I am confused about whether she actually perceives the stigma to be present. She does not seem to be affected by being her HIV status and appears to be frustrated that I would think that she was.

I decide to clarify with another question. When I ask about whether she has faced any discrimination, she replies, “I can only say for myself, but at the places I’ve worked, people have always been compassionate. I have never had anyone shy away from me because of me being HIV-positive. There is still a stigma where people are ignorant, but if it happened to me, I would still laugh and go on. You’re the ignorant one. I don’t want to hate anyone—it takes too much energy to hate. But I will never belittle myself. You go your way and I’ll go mine.”

She proceeds to read a moving poem to me that she wrote about loving herself, and as she speaks, her eyes begin to tear up. At that moment, I can visibly see the pain that she has endured. Lisa has faced many challenges that have not just been about HIV. Her journey has been a long, arduous one, but somehow, she has managed to emerge through the darkness with strength and humility with the support of true friends and loving family. She became upset because my questions about her experiences with stigma may have had the unintended consequences of generalizing her story.

Although I did not realize it at the time, Lisa was trying to tell me something behind her answers: her HIV status does not define who she is. Instead, she has the power to choose how to live her life. Lisa refuses to allow the negative projections of HIV/AIDS to control her experiences, but rather, she has found strength in discourse, through her decisions in disclosing her status and through writing poems. While stigma may affect how others view her and consequently the way in which she navigates her life, ultimately, she has the power in her ability



to resist, to tell, and to share. Chapter 4 explores the ways in which those affected with HIV/AIDS claim agency in forging their own stories and experiences, thus reconfiguring the status of stigma. Although I recognize the strength that people can have through discourse, at the end of this chapter, I will also return to politics to examine how personal voice can be both liberating as well as oppressive.

### **Return to Goffman**

As I have mentioned earlier, Goffman's analysis of stigma has had extensive influence in shaping the discourse presently surrounding stigma. He refers to a stigmatized person as having a "spoiled identity" and explores how the stigmatized can react to protect themselves from negative perception, dealing with stigma through identity management.<sup>151</sup> While Goffman's work resulted in greater attention to the lives affected by stigma, his conceptions have contributed to a view in which stigma is located within an individual rather than extended to encompass society, as is the pillar of neoliberalism. Because Goffman's theorization of stigma primarily focuses on the individual as the site of intervention, this has reinforced the neoliberal understanding that responsibility and intervention lies within a singular body. Although Goffman may not have anticipated these effects when he was writing, I believe it is important to deconstruct his theory of stigma to illuminate how his conceptualizations have affected the state of HIV/AIDS in today's neoliberal society, especially since so many scientists invoke his definition of stigma in their studies. How has Goffman's theory converged with neoliberalism to promote the idea that stigma is a generalizable private attribute rather than as a social phenomenon that dynamically changes with context?

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<sup>151</sup> Goffman, *Stigma*.

In discussing how stigmatized individuals manage personal identity through informational control, Goffman describes how a “very widely employed strategy of the discreditable person is to handle his risks by dividing the world into a large group to whom he tells nothing, and a small group to whom he tells all and upon whose help he then relies; he co-opts for his masquerade just those individuals who would ordinarily constitute the greatest danger.”<sup>152</sup> While Goffman recognizes the ability of individuals to selectively disclose information, his reference to a masquerade hints that deception in relationships is needed to protect oneself, mirroring the notion that those who are HIV-positive must remain confidential about their statuses to mitigate stigma. The idea of strategy and risk management in decision-making also echoes the dialogue disseminated in the neoliberal controlled business world, which place the responsibility in privatized bodies to react to the world in the proper way. Thus, the inability to successfully respond to risk becomes seen as a result of individual failure rather than structural forces.

According to Goffman, voluntary disclosure can be one of the methods of risk management, and if one chooses to disclose, he can “radically [transform] his situation from that of an individual with information to manage to that of an individual with uneasy social situations to manage, from that of a discreditable person to that of a discredited one.”<sup>153</sup> While management is once again mentioned here, Goffman’s analysis provides another perspective of stigma that is less about the individual and more about social ties. He differentiates between the terms “discreditable” and “discredited” to highlight the shift in focus towards a society that does the stigmatizing, but many studies of stigma do not reference the significance of these terms. Instead, they describe a stigmatized person as “discreditable,” and without discussion of the

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<sup>152</sup> Ibid., 95.

<sup>153</sup> Ibid., 101.

framework of the word, this label can serve to perpetuate the notion that a stigmatized person is inherently disgraceful and perpetually separate from the rest of society.

By evaluating Goffman's theory of stigma in relationship to current neoliberal ideals and scientific studies, we can see how invoking characterizations of stigma without context can create a problematic structure in which people become strapped to their marks of stigma, and their responses are seen as reactions to stigma. How then, might we move beyond this perspective to evaluate disclosure?

Instead of viewing stigma as a stain that leads to fixed pathways of private reaction, I will explore the context behind instances of disclosure to show how the dialogue represents more than just an assertion of self-esteem or an affirmation of morality. In the face of silencing by the state, maintained through national ideologies of neoliberalism and expectations of confidentiality, voluntary disclosure does not signify a coping mechanism, but rather, indicates a sign of agency. People can produce discourse in dynamic ways, and the dialogue operates within different spaces for different ends. Through this negotiation of stigma, those affected by HIV/AIDS can produce words to empower the self and to empower others.

## **The Power of Discourse in Reshaping Stigma**

### Stigma and the Self

Discourse has influence in shaping stigma by selectively encouraging dialogue amongst those who are healthy while promoting silence for those affected by HIV/AIDS, effectively skewing our perceptions. Those who are not affected by the disease do the speaking for those who are affected, and through this partiality, we may be inclined to overlook the diverse experiences of those living with HIV/AIDS. However, I will show that those living with the

disease can also be actors who employ words to negotiate stigma, and I will return to Foucault to highlight the power of discourse.

Relating knowledge to power, Foucault emphasizes how power stems from multiple forces, exercised from many institutions and many individuals that are contingent upon each other, and discourse can be the source of these struggles for power.<sup>154</sup> As Foucault argues, “We must make allowances for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it.”<sup>155</sup> Approaching neoliberalism as discourse can further illuminate the agency that people can have in employing discourse for their own means. In the realm of HIV/AIDS, while neoliberal forms of discourse may dominate our world in the policies, laws, and care structures in place, people also have the power to resist through their words. My participants have shown the variable ways in which they engage in dialogue for empowerment.

After a long journey of both societal and self-rejection, in which Irene felt isolated from everyone due to the stigma of her disease, Irene eventually finds power in speech. She describes to me how composing poems ultimately help her to overcome her disease, revealing,<sup>156</sup>

*“For a long long time I was angry. I started to write poems. I put a voice to me having HIV.”*

Irene’s reclamation of a “voice” indicates that she did not feel as if she possessed one when she was first diagnosed. The stigma surrounding the HIV/AIDS affected her ability to speak about

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<sup>154</sup> Michel Foucault, *The History of Sexuality: An Introduction* (Hammonsworth: Penguin, 1978).

<sup>155</sup> *Ibid.*, 101.

<sup>156</sup> Irene (HIV-positive participant) in discussion with the author in September 2013.

her experiences, but when she finally forms the words, she asserts control in representing herself rather than allowing others to generalize her life as a mere “discredited” person. Irene shares two of these poems with me, which I have included here:<sup>157</sup>

POEM 1:

*That was then this  
is now. I look back  
but move forward. I love  
who I am and all that  
I am, I'm a woman  
All woman superwoman  
because  
of you I learned me I  
Am every women. I learned  
to love me so that I  
could be the woman!*

POEM 2:

*I look up I look  
down I look all around  
All I see is me, I look  
At you I look at me  
me where would I be. One  
thing I can say I am  
glad to be free to  
be me*

Like Lisa, who also composed poems, Irene’s internal dialogue provided an outlet for her to express herself, even when the words were written and not spoken. Irene began to gain confidence in herself as a person who could defy, illustrating the power that discourse has in shaping relations to power. Words represented her thoughts and actions in ways that stigma could not predict. By recovering her voice, Irene no longer felt as if she was a singular entity secluded from society, but as a participating member of the dialogue that surrounds the disease. In this moment of empowerment, Irene looks towards the future in which she no longer acquiesces to the identities that stigma anticipate, and instead, she becomes freed from the bonds of stigma through dialogue. While the dominant discourse of individualism may have led her to believe that she was alone in the past, discourse has also allowed for spaces of negotiation in which words replace the silence. Irene seizes agency in going against the confidentiality measures that society emphasizes.

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<sup>157</sup> Ibid.

### Stigma and Others: Sharing Stories

Although the everyday may be infused with neoliberal ideals, people can have power in the ways they oppose, and speaking publicly can also be a means of doing so. Disclosure is no longer selective, but rather, readily available to all. By responding against the norms of silence about HIV/AIDS, Irene demonstrates her resistance as she reveals to me,<sup>158</sup>

*“I didn’t want anyone to go through what I went through. I started telling my story publicly, and a lot of people told me they wouldn’t have known about my HIV status if I hadn’t told them.”*

After experiencing seclusion from others in which Irene felt as if she had no one to talk to, Irene decided to share her story publicly so that others may not feel the same way. Irene realizes the power of stigma to produce expectations of silence, which enhances sensations of isolation. In a roundabout way, the secrets only further instantiate stigma.

Words not only empower the self, but when shared with others, stories can also create a dynamic network of exchange in which others can realize the power in discourse. By breaking down the walls of silence, people may no longer feel isolated from each other, but rather, they can come to see experience as contingent upon many people and certain ways of thinking. A macroscopic view replaces the microscopic one, and through this lens, we can more critically evaluate stigma as a phenomenon that not only affects individuals, but also forms as an extension of society. Irene further reveals,<sup>159</sup>

*“It makes me sad that so many people feel like they need to hide it. There are so many newly diagnosed people. They don’t have anybody to talk to or can’t. At one of the events I spoke at, a lady came up to me and told me I spoke her pain. If I can just help one woman or one person be able to talk, I feel like I’ve done something.”*

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<sup>158</sup> Ibid.

<sup>159</sup> Ibid.

Irene inserts her own unique experiences into the extant arena of publicly formed discourse and uses the dialogue not to propagate notions of fear and contamination, but rather to relate to others. People negotiate stigma in such a way that negative perceptions no longer generate identities and lead to the expected reactions. By connecting to others through conversation and by encouraging exchange, Irene helps others to bypass the anticipated stigma that appears to be synonymous with HIV/AIDS. Such commensurate relationships create an environment in which silence no longer reigns as a mechanism of stigma. Instead, words are spoken so that people can bypass stigma.

Irene tells me about a recently launched social media campaign that relies on the voices of PLWHA to combat stigma. The Rise Up To HIV Facebook page shows a logo that advocates for “voices in unity” in “strengthening community,” echoing Irene’s point about how placing a voice to her disease can be empowering.<sup>160</sup> The group has generated a few albums entitled the Summer of No Shame, and the album description reads:

“Launched in January of 2013 the “No Shame” campaign quickly grew and now has over 500 photos AND stories becoming the largest collection of public testimony from Individuals LIVING with HIV/AIDS, and the largest HIV anti-stigma campaign based solely on social media. The campaign has gone viral with over 10 million people reached, tens of thousand of comments, and 500,000+ likes combined on all photos.

The page has become a safe space for people to come out about living with HIV or AIDS. The AIM of these stories is to empower others to know their status, to live unafraid of an HIV diagnosis, and to continue to dream big and live out those dreams.

This campaign is very engaging and compliments multiple components of the HIV care continuum. Through first hand accounts individuals feel empowered to get tested, to start or remain in care, and to share their story in hopes of helping others. The campaign is reducing stigma one photo, one story at a time.”<sup>161</sup>

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<sup>160</sup> “No Shame About Being HIV Positive (Album 1),” accessed March 3, 2014, <https://www.facebook.com/media/set/?set=a.445611775499636.105360.191006750960141&type=3>.

<sup>161</sup> Ibid.

Demonstrating the power of dialogue, the album contains many stories and quotes from people who are HIV-positive, accompanied by pictures of a diverse group of people. This campaign shows how experiences are unique and cannot be generalized, but at the same time, dialogue can be powerful in its ability to relate to others and to reshape stigma. The campaign facilitates conversation throughout society, and the networks of communication remain open so that stigma no longer one-dimensionally operates within an individual. Even in the support group I attended, sharing stories helped the women in the group relate to each other and to reaffirm each other, reminding them that they are not alone in their disease.

Dialogue not only produces ties to the greater community, but for those living with HIV/AIDS, the decisions to disclose also bring familial relationships to the forefront. When Irene first wanted to speak publicly, she reveals that she first asked her children how they would feel, as she worried about how the stigma of having an HIV-positive mom may affect them. Even before my interview with Irene, she had asked her children whether they approved of her decision to speak to me. Only with their full support and encouragement did Irene decide to speak out.

Furthermore, Rhonda tells me how she had similar discussions with her children when she was considering public speaking.<sup>162</sup>

*“I spoke out for the first time in 2008, but before that, I was contemplating for two years because I was concerned for my children. I was concerned about my status going back them and how they were going to take it. I had to discuss it with all my children about what I wanted to do, that I wanted to put my name out there, and how they would feel. They gave me the courage to write my story, and it felt really good to put my story out there and to hear feedback from the community.”*

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<sup>162</sup> Rhonda (HIV-positive participant) in discussion with the author in December 2013.



In this complex exchange, we can see that those living with HIV/AIDS are still vulnerable to stigma, yet the discussions about disclosure with their family remind us of how people are always intimately connected. Recognizing the ties that one has to family and friends, Irene and Rhonda both consult their children even though the disease may appear to be an isolating one. Neoliberal discourse may create the illusion that individuals are remote to such an extent that the stigma becomes embodied, but Irene and Rhonda have employed discourse to illuminate the social ties that are inextricable from everyday life. Those who are not directly infected by HIV/AIDS can still be affected by the stigma. By speaking in public, Rhonda receives input from community members, who engage in the exchange about stigma as much as those who are living with the disease. Negotiations of stigma can occur at a broader level that encompasses everyone in the community, bringing the social production of stigma into question.

As Rhonda reminds us of the power of speech in highlighting our links to each other,<sup>163</sup>

*“I will put it out there to tell people this is my testimony to show that we need to love people and to compliment people. This is all a person needs to get them to where they need to be.”*

Dialogue can both empower and remind us of our connections to each other in negotiations of stigma. By reforming connections that have been threatened through the encouragement of silence, words can illuminate the commensurability of the world.

### **Tensions of Disclosure**

By evaluating the context of these stories of disclosure, I have aimed to show how the lived experiences of HIV/AIDS are complex and dynamic and how voluntary disclosure is not just a reaction to manage stigma. Instead, words can be powerful in how and when people deploy

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<sup>163</sup> Ibid.

them to challenge the dominant conversations in society, which signifies a deliberate attempt to assert agency through conversation with the self and others.

However, in light of the neoliberal politics and ideologies that pervade the American way of life, I would like to complicate the role of discourse further. The dominant forms of discourse surrounding HIV/AIDS in politics, culture, and medicine have exacerbated inequalities according to race, class, and health, making life for those affected by the disease extremely difficult. Besides functioning in an emancipatory role, then, in what ways can discourse be repressive?

As Nguyen demonstrates, confessional technologies such as public testimonies “instantiate a relationship to an inner self that [can] be examined, prodded, and told,” thus relying on the same neoliberal ideals of self-help explored in earlier chapters.<sup>164</sup> The individual becomes the focal point of intervention, and through disclosure, one can access an inner truth. When my participants express instances of finding their voices, these moments fall within the expectations of confessional technologies in which disclosure works to discover a more valid self. The politics surrounding HIV/AIDS have devalued their bodies based on their disease, so they are required to take on the personal responsibility of discovering a different person that has overcome the virus.

By fulfilling these expectations of neoliberalism through testimony, then, confessional technologies can also act as “political technologies, reproducing forms of power between individuals and ‘agencies’ that require the confession.”<sup>165</sup> While disclosure can be employed to confront and destabilize stigma, the decision to reveal an HIV diagnosis can also inadvertently reproduce hierarchies of power. The complex intersections of political economy, history, and

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<sup>164</sup> Nguyen, *The Republic of Therapy*, 39.

<sup>165</sup> Ibid.

ideologies have created the framework in which silence is expected in some instances and disclosure is advocated for in other moments. Some will inadvertently have the opportunity to speak out during the right times while others do not, and in these ways, discourse can serve as a tool for maintaining the neoliberal regime. Although my participants have demonstrated the liberating role that disclosure can have in light of anticipations of confidentiality, their stories can also show the limitations of discourse.

## Conclusion

On my way to class, I often pass by student groups who are at tables advocating for their organizations and promoting their events. One table in particular always catches my attention. Hanging from the tabletop, a large banner conspicuously reads “Get Tested” and a red ribbon, the universal symbol for HIV/AIDS, trails these words. The students who staff the table attempt to lure in bystanders with candy and condoms, and they are familiar faces in the sea of Duke blue. With a relatively small class size, it is impossible not to recognize at least a couple of people everyday. Sometimes, I see many students clustered around the table, and other times, those behind the table are the only ones present. Aiming to reduce stigma around HIV by launching a collective effort to get tested, the group who runs the Get Tested campaign encourages testing to increase health awareness and to show solidarity with those who are HIV-positive. The idea is that by recruiting more people to be tested, a multitude of faces will come to represent the disease, lessening stigma by showing that a fixed stereotype does not exist. Those who face uncertainty about their status can then get tested within this approachable environment.

When I interview Jo, a student who is involved with the campaign, she expresses to me how stigma paradoxically serves as a barrier in testing even though reduction of stigma is the group’s aim. She tells me,<sup>166</sup>

*“When we ask people if they want to be tested when we’re tabling, people say no, I don’t have HIV. You can tell by their body language that they don’t want to be seen taking a condom or be seen talking to someone about HIV.”*

Some students do not wish to be associated with the disease, and when I ask Jo why she thinks students behave this way, she responds,<sup>167</sup>

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<sup>166</sup> Jo (Duke student) in discussion with author in October 2013.

*“For some people, it’s the stigma of being sexually promiscuous. Like why do you need a test in the first place?”*

Whether one is infected by the disease or not, stigma affects everyday life. In their decisions in being tested or not, everyone confronts the stigma of HIV/AIDS. Those who ultimately decide to go through the process of becoming tested, whether through concern for their status or whether to show support for those living with HIV/AIDS, are then generalized to be of a certain moral order. With such good intentions of lessening negative perceptions, why then, does this campaign invoke the very same issues of stigma? Through mechanisms that become normalized via dominant discourses of neoliberalism, the power of stigma to shape lived experiences can infiltrate our worlds in ways we may not realize.

As my fieldwork began to wrap up, I decide that it is my turn to get tested for HIV/AIDS. When I approach the table after class, I declare that I am here to be tested, and one of the students responds, “Take a number and tell it to me. This is for your confidentiality.” I am caught off guard by his reference to confidentiality, but I take his words into stride and sit at the table, waiting for my turn for the test. As people walk by the table, I cannot help but notice the expressions. Some look uncomfortable and avert their eyes, while others give me judgmental looks, as if to question my intentions for being there. How will the number protect my privacy when I am in a stigmatized space where I recognize students, and they recognize me? What is the meaning of confidentiality in this context, and would not the emphasis on anonymity contradict the organization’s goal in achieving solidarity through testing?

After waiting for a few minutes, one of the students notifies me that a room has opened, and I go with him and another girl to begin the test. In the room, a table displays packets of Ora

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<sup>167</sup> Ibid.

Swab and stacks of paper. The students give me a questionnaire to fill out, and on top of the page in capital letters and bold font, confidentiality is mentioned yet again. Lower on the page, CONFIDENTIALITY is featured prominently as well. When I return to the testing site half an hour later to get my results, I can clearly see others students' questionnaire answers, which are conspicuously placed next to the corresponding test results. I could not help but note the irony of confidentiality in this case.

Time and time again, I am confronted with how pervasive the notion of confidentiality is in our American society. My original research question focused on how stigma can overlap and how these intersections can inform identity, but as my fieldwork progressed, I found that there is more to the story than just the internalization of negative perceptions. Instead, stigma has provided a useful lens in examining broader issues by allowing me to explore the context behind the tension of disclosure versus confidentiality.

Because I recognize that silence can also be a form of discourse that people can employ to negotiate stigma, I was initially reluctant to provide a critique of confidentiality. The decisions not to disclose a status can be practical, especially when those who are HIV-positive do not have social networks of support to rely on in sharing their diagnoses. However, as I began to notice how neoliberal rhetoric pervaded policies, laws, and even in my dialogue with participants, I wondered how confidentiality could serve to instantiate neoliberal ideals. Besides alleviating stigma for individuals, do the expectations of secrets serve a greater purpose?

In the context of HIV/AIDS in Durham, neoliberalism has concretized notions of individualized, bodily responsibility and has created certain narratives of attribution so that when a person is diagnosed with the disease, he or she may see no other option but to internalize the disease. These neoliberal rationales of thinking and operating tell us that there are certain secrets

that one must keep for protection from stigma. Confidentiality is founded upon the premise that stigma is as an inherent aspect of living with HIV/AIDS, which further maintains the separation between those who have the power to stigmatize and those who must respond to the stigma.

While confidentiality could benefit a person in some moments, in others, the lack of discourse on one side inevitably permits other types of discourse to reign, and I wanted to show how confidentiality can be problematic in these ways.

These dynamics between visibility and invisibility were also prevalent at the 5K race I attended, though I did not realize it at the time. Maybe the race had low attendance numbers because issues of HIV/AIDS are constrained to a specific group of people in the Durham community, whose stories are overlooked because they are insulated through expectations of confidentiality. Or alternatively, because neoliberal policies have limited the funding available for those affected by the disease, perhaps that is why we see low-scale advocacy events where candy and condoms are distributed rather than large-scale calls for equal healthcare.

Throughout my research, I also often wondered about the significance of my participant pool. Those who decided to speak with me are also the ones who are also most likely to be comfortable with public testimonies, but what about those who would rather not share their diagnoses? By including context, I hope to have illuminated the specificity of my fieldsite while demonstrating the value in analyzing my participants' stories in light of the policies, laws, histories, and care structures that shape their everyday lives. Their experiences highlight the ambiguities in how people respond to stigma, as well as the political nature of voice. While disclosure can be powerful in combating dominant narratives of isolation and silence, discourse can also be a neoliberal trap in which ideals of self-intervention are reproduced, and my participants' stories demonstrate both the advantages and limitations of discourse.

Instead of perpetuating these dichotomies between speaking out versus remaining silent, then, it might be more productive to reshape the discourse surrounding HIV/AIDS altogether. Just as stigma affects both those who are infected by the disease and those who are not, discourse also touches everyone. Instead of viewing discourse as an individual voice that either asserts agency or perpetuates inequalities, we can change the way in which we discuss society by viewing voice as a phenomenon that incorporates multiple perspectives. By implicating everyone in a voice, we can emphasize the world's interconnectedness to illuminate how discourse can shape everyday relations and identities, and perhaps then, we can move beyond the "it is what it is" mentality in which stigma is seen to be universal.



## Bibliography

- Adams, James T. *The Epic of America*. Boston: Little, Brown, and Company, 1931.
- Adler, Nancy E. "Overview of Health Disparities," in *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*, edited by Gerald E. Thompson, Faith Mitchell and Monique B. Williams, 129-188. Washington: National Academic Press, 2006.
- Aidala, Angela, Jay E. Cross, Ron Stall, David Harre and Esther Sumartojo. "Housing Status and HIV Risk Behaviors: Implications for Prevention and Policy." *AIDS and Behavior*, 9 (2005): 251-265.
- AIDS.gov. "A Timeline of AIDS." Accessed December 3, 2013. <http://aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline>.
- Atripla Peer Advocate Network, "Making Changes: Cyrano's Journey with HIV."
- Barnett, Clive. "The Consolations of Neoliberalism." *Geoforum* 36 (2005): 7-12.
- Benson, Peter. *Tobacco Capitalism: Growers, Migrant Workers, and the Changing Face of a Global Industry*. New Jersey: Princeton University Press, 2012.
- Bondi, Liz. "Working the Spaces of Neoliberal Subjectivity: Psychotherapeutic Technologies, Professionalisation and Counselling." *Antipode* 37, no. 3 (2005): 498-514.
- Brada, Betsey B. "How to do Things to Children with Words: Language, Ritual, and Apocalypse in Pediatric HIV Treatment in Botswana." *American Ethnologist* 40, no. 3 (2013): 437-451.
- Centers for Disease Control and Prevention. "Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?" Accessed April 2, 2014. <http://www.cdc.gov/hiv/risk/other/poverty.html>.
- Centers for Disease Control and Prevention. "HIV Among African Americans." Accessed April 2, 2014. <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>.
- Centers for Disease Control and Prevention. "HIV in the United States: *At a Glance*." Accessed December 4, 2013. <http://www.cdc.gov/hiv/statistics/basics/ata glance.html>.
- Centers for Disease Control and Prevention. "HIV/AIDS Programs." Accessed December 4, 2013. <http://www.cdc.gov/hiv/prevention/programs/>.
- Duke AIDS Policy Project. "Health Care Reform." Accessed February 5, 2014. <http://dukeaidspolicyproject.com/health-care-reform/>.

- Foucault, Michel. *The History of Sexuality: An Introduction*. Hammonsworth: Penguin, 1978.
- Foucault, Michel. "The Order of Discourse," translated by Ian McLeod in *Untying the Text: A Post-Structuralist Reader*, edited by Robert Young, 48-78. Boston: Routledge & Kegan Paul, 1981.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, Inc., 1963.
- Gregory, Sam. "Magic Johnson and HIV: The Lasting Impact." *Time*, November 7, 1991. Accessed December 3, 2013. <http://keepingscore.blogs.time.com/2011/11/04/magic-johnson-and-hiv>.
- Harvey, David. *A Brief History of Neoliberalism*. Oxford: Oxford University Press, 2005.
- Health Resources and Services Administration. "Who Was Ryan White?" Accessed December 3, 2013. <http://hab.hrsa.gov/abouthab/ryanwhite.html>.
- Henry J. Kaiser Family Foundation. "Attitudes about Stigma and Discrimination Related to HIV/AIDS." *Kaiser Public Opinion Spotlight* (2006).
- Henry J. Kaiser Family Foundation. "The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid." Accessed April 3, 2014. <http://kff.org/health-reform/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>.
- Herek, Gregory M., John P. Capitanio and Keith F. Widaman. "HIV-related Stigma and Knowledge in the United States: Prevalence and Trends, 1991–1999." *American Journal of Public Health* 92 (2002): 371–377.
- Mahajan, Anish P., Jennifer N. Sayles, Vishal A. Patel, Robert H. Remien, Daniel Ortiz, Greg Szekeres and Thomas J. Coates. "Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward." *AIDS* 22, suppl. 2 (2008): 67-79.
- Martin, Emily. *Flexible Bodies: Tracking Immunity in American Culture—From the Days of Polio to the Age of AIDS*. Boston: Beacon Press, 1994.
- McAllaster, Carolyn. "Protecting the Confidentiality and Security of Sensitive Health Diagnoses like HIV in North Carolina." Manuscript prepared for health practitioners, Durham, North Carolina, June 2013.
- McGregor, Sue. "Neoliberalism and Health Care." *International Journal of Consumer Studies* 25, no. 2 (2001): 82-89.
- "National HIV/AIDS Strategy for the United States." Last modified July 2010. <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>.

- Nguyen, Vinh-Kim. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham: Duke University Press, 2010.
- Rhine, Kathryn A. "Support Groups, Marriage, and the Management of Ambiguity among HIV-Positive Women in Northern Nigeria." *Anthropol Q* 82, no. 2 (2009): 369-400.
- Rise Up to HIV. "No Shame About Being HIV Positive (Album 1)." Accessed March 3, 2014. <https://www.facebook.com/media/set/?set=a.445611775499636.105360.191006750960141&type=3>.
- Springer, Simon. "Neoliberalism as Discourse: Between Foucauldian Political Economy and Marxian Poststructuralism." *Critical Discourse Studies* 9, no. 2 (2012): 133-147.
- State of North Carolina: Governor Pat McCrory. "Governor McCrory Recommends Healthcare Implementation Strategy." Accessed February 5, 2014. <http://www.governor.state.nc.us/newsroom/press-releases/20130212/governor-mccrory-recommends-healthcare-implementation-strategy>.
- U.S. Department of Health and Human Services. "Read the Law." Accessed February 5, 2014. <http://www.hhs.gov/healthcare/rights/law/index.html>.
- Weinberg, Rick. "7: Magic Johnson Announces He's HIV-positive." Accessed December 2, 2013. <http://sports.espn.go.com/espn/espn25/story?page=moments/7>.
- Whelehan, Patricia. *The Anthropology of AIDS: A Global Perspective*. Gainesville: University Press of Florida, 2009.
- Yang, Lawrence H., Arthur Kleinman, Bruce G. Link, Jo C. Phelan, Sing Lee and Byron Good. "Culture and Stigma: Adding Moral Experience to Stigma Theory." *Social Science & Medicine* 64 (2007): 1524-1535.