RECONSTRUCTING RESPECT FROM THE MARGINS: TOWARDS A MORE

COMPASSIONATE HEALTHCARE POLITICS

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Summer Internship Experience

This past summer was the first time I could truly say I have ever been “down for the cause,” and had tangible evidence to back it up. I was no longer the white boy concerned with minority affairs from behind a classroom desk, but the young, hopeful college intern thrown into the middle of the action in a cutthroat, winner-takes-all political warzone. While there are many great experiences and lessons that I have taken away from my experiences in DC, if I had to boil it down to one, it would be that “being down for the cause” more often than not falls back to the same types of discriminatory and exclusionary practices that brought about the “cause” in the first place. That is, that even when one has the purest of hearts, and the best of intentions, and all their life’s work has become dedicated to helping others in need, that we still easily fall prone to appropriating harmful stereotypes, we still exclude or downplay the input of others who from first appearance don’t seem like they’re also “down with the cause” or who are less versed than us in the subject matter, or we simply target another individual or group to subordinate as a means of compensation for our own pains and discomfort.

For me, the “cause” I got down for this summer was HIV/AIDS healthcare policy work—specifically, the implications of the Affordable Care Act (aka “ACA,” “Obamacare”) Supreme Court ruling for people living with HIV/AIDS (PLWHA) in the U.S. The organization I interned with is a well known, national nonprofit located in central DC in a historically black, impoverished district. My summer’s work included electronic reading and research of the Court ruling and topic, attending
Capitol Hill briefings, listening in on conference calls with other nonprofits and community-based organizations (CBOs) on the implications of the ruling and reauthorization of the Ryan White Care Act (aka “RWCA,” an act of legislation in place providing critical financial support and wraparound services for PLWHA in need of care nationwide), discussions with renowned members of the HIV/AIDS community, participating in organized marches on Pennsylvania Ave, attending the 19th International AIDS Conference (“AIDS 2012,” the “IAC”) and blogging about the Conference events I attended for my organization. Through my internship experiences, I was placed at the center of HIV/AIDS policy and the community, and truly “took the cause on as my own” for the entirety of the summer. The summer was no less than eye opening.

Many dreams came true during this journey—meeting “very important persons,” traveling to and living in DC for my first time, interning at a nonprofit organization doing legal/policy research and work, and taking classes at a prestigious university—throughout the summer, yet even while all this was rewarding I could not help but notice old habits of marginalizing unwanted “others” being practiced on a consistent basis, simply having been repackaged in a different form—and this was within a community widely recognized as a “target,” “marginalized,” “at-risk” population! Now, however, the undesirable “others” subgroup had simply changed to those outside of the HIV/AIDS community, who are often stereotyped as uncaring or ignorant of issues facing PLWHA, or those within the HIV/AIDS community (including individuals already affected with HIV/AIDS, friends and family members
of PLWHA, and those who are framed as being particularly “at-risk” for contracting the virus) who didn’t meet other prerequisites for inclusion. Of course, the basis for these requisites depended in large part on the HIV/AIDS demographic subset you were working with.

For instance, when working with advocacy organizations representing Latinos with who HIV+, discussions came up about the lack of cultural competency of the average American when it comes to the intersecting difficulties of assimilating to the English language and being a sexual “deviant”; or being an out GLBT Latino who is not a native speaker; or the lack of familiarity on the part of non-Latinos with the concepts of Familismo or Caballerismo, and how these compound with other intersecting social factors to make their lives particularly difficult. Or, when talking amongst all- or mostly all-black HIV/AIDS CBOs, about the compounding effects of being young, black and poor, and being especially “at-risk” for HIV/AIDS because of the sociopolitical environment one was born into, there is still that lingering sense that other people of color within the HIV/AIDS community still cannot fully grasp the gravity of the situation for blacks because of the uniqueness of the American black-white divide (as if the racial divide amongst any other two racial groups has not been unique in America, or as if the similarities amongst people of color within the same HIV/AIDS community cannot be seen as an overriding, more important commonality yet). Or, if one is amongst a diverse group of HIV/AIDS members writ large, there is still a very strong divergence between those who contracted the disease heterosexually versus those who contracted the disease homosexually, or between those who are not
in incredibly good health and those who are (which has become a form of compensatory subordination for GLBT members), or between those who know the medical terminology associated with HIV/AIDS policy and those who do not.

No matter which subgroup within the HIV/AIDS community I happened to be working with or focusing on during any given day for my work, I always managed to find familiar practices of ordering and discrimination, disgust and disrespect that I previously thought were prevalent solely or mostly within mainstream American institutions and practices. How wrong was I! Being a student who has studied marginalized populations in-depth for several years now, I had naïvely hoped that coming to DC and finally working with a demographic I’ve specifically studied, that acts and attitudes of discrimination and habits of disrespect would not be as rampant as they were within mainstream American culture (my logic being that people who have experienced exclusion and discrimination on a continual basis for all their lives must know better…which I realize is problematic logic in and of itself, but is what I was still hoping for). This simply was not the case. Old forms of discrimination, disgust and disrespect had been modified to accommodate the needs of an already marginalized demographic.

The moment when I finally gave in to reality happened to be at an event I attended for the IAC. At this meeting were several panels of discussants, including renowned individuals such as the Surgeon General, the head of medicine at one of the National Institutes of Health (NIH), and the Secretary of Health and Human Services (HHS) among other prominent participants. And it was during one of these panel
discussions when one of the panelists finally brought up the issue of language used in HIV/AIDS policy, and how this language can be just as detrimental to “the cause” as the stigma and forms of personal and institutional discrimination community members face in mainstream culture on a regular basis. Specifically referencing phrases such as “PLWHA are a target population,” “at-risk,” “vulnerable populations,” and much of the medical terminology that one would not be familiar with outside of the HIV/AIDS policy arena, the panelist highlighted the stigmatizing/exclusionary characteristics of practices and policies within the community itself, effectively airing out the discussion and resonating with this troubled sense that had been building in me all summer long.
Prologue

To bring up these issues and complain about all the negative aspects of my internship experience is not the point of why I began with this introduction. However, the story begs the question, “Why write about all of this?” The fact is that I feel troubled about the forms of prejudice and discrimination that took place back in DC; not because it is the nation’s capitol, and the people there should know better but because I had been thrown into the heart of community involvement and policy engagement for a group of individuals and families who have for decades themselves been the victims of marginalizing and denigrating practices due to their social identities, and who have struggled equally as hard as the next group for their right to participate as first-class citizens in this country.

And, fair enough, one may then ask, “But why do I care? Why should I be concerned with how this community and these individuals conduct their lives in pursuit of their dreams?” My response is that it evokes a sense of injustice and inequality, plain and simple. I see the modification of mainstream practices of discrimination, disgust and disrespect (by the HIV/AIDS community) into new, more masked forms of power-grabbing oppression as equally as troublesome as the last set. The situation parallels that of fighting violence with more violence, or Hammurabi’s “an eye for an eye” code—the “solution” will not solve the problem, because the “solution” relies on the problematic tendencies and practices themselves. And at the root of these feelings is the American dream, or what I shall call the “egalitarian ideal.” The ideal posits that we as a nation are a community collectively working
towards legal equality and equal opportunity for all citizens, regardless of their race, class, and gender. And the customs that I mentioned above from within the HIV/AIDS community violated this claim.

By no means is the HIV/AIDS community fully to blame for the bad habits and practices I noticed during my summer in DC. Nor should my depictions of the forms of discrimination be taken here to be representative of the HIV/AIDS community as a whole. However, the forms of discrimination and disrespect mentioned herein were real acts, which were carried out by real actors, and which claimed real victims. They were widespread in that I did not find all of these habits through the course of one single week in DC, but, rather, throughout the course of the entire summer when I was attending different events with different people on a daily basis. And my experiences here made me think, what if these modified, nuanced forms of mainstream discrimination, disgust and disrespect were rampant amongst all communities and demographic populations? More specifically, what if all- or mostly-all already marginalized populations practiced these exclusionary, marginalizing habits? What does this say about the American dream, and what does this say about how we as fellow human beings are achieving “progress?”

In truth, there are hundreds of answers to these questions depending on which demographic groups one looks at, the context in which they view this population, one’s own personal experiences with a certain group or groups, how one defines the “egalitarian ideal,” how one defines “disrespect,” and how one perceives “progress.” Thus, I will narrow my scope. In this project I will begin to interrogate the practices of
marginalization, disgust and disrespect in the American democratic context from the point of view of marginalized populations. Focusing on the disgust as an orientation through which people practice disrespect, I will define what each of these terms means respectively, and provide a grounded analysis of each through concrete, real life examples. While my scope encompasses marginalized populations in general, the examples provided for analysis henceforth will be particular, and will include issues within the HIV/AIDS community with which I worked. I contend that not only do the examples of disgust and disrespect evoke feelings of injustice and inequality on a personal level, but that they are problematic and even inimical to the egalitarian ideal.

In this project I also hope to move beyond simple analysis of disgust and disrespect to provide a working solution to some of the problems we find with the egalitarian ideal. Through the lens of deliberative democracy I will explain why more inclusive, egalitarian practices are desirable and necessary if we are to continue to pursue our espoused claim of every individual being able to “live the American dream.” In working through concrete examples of discrimination, disgust and disrespect I will provide a grounded analysis of an alternative appeal to mutual respect as a tool that can bring us closer to this ideal. I will define mutual respect as both an orientation through which we should approach democratic processes, as well as a practice that we should foster and improve upon through regular use. Through interrogating the concept of “respect,” I will illustrate the deficiencies of respect as we currently perceive it. I work through issues of respect via the dominance of experts in particular deliberative settings and the lack of consciousness given to the language and
logic we use when talking about marginalized populations as baselines for where we can construct a practical notion of mutual respect that fosters more inclusive, egalitarian democratic processes.

The underlying theme throughout this project will be the political importance for democracy of a revised notion of “respect.” The concrete examples I give of legislation and policymaking henceforth will evidence the deficiencies of current notions of respect. Through these examples, we shall glean that disgust can be seen as a more general mechanism for marginalization, and that it is often practiced by—yet just more deeply hidden in—communities that are already perceived to be “vulnerable populations.” Through “reconstructing respect from the margins,” I will offer a unique, working solution to the troubles we face under the egalitarian ideal. In recognizing that the forces that shape deliberative settings themselves are inegalitarian, I will argue that we must use mutual respect as a tool towards more inclusive, egalitarian processes, while still realizing that we may never reach “perfection.” However, by viewing “progress” as coming closer to the egalitarian ideal, instead of some finite point of achievement or perfection, we will have a much more practical sense moving forward of how mutual respect can improve our democratic processes and bring us ever closer to achieving the egalitarian ideal.
Introduction

For over thirty years now, HIV/AIDS has been regarded as a domestic epidemic that is plaguing the nation. Framing the illness in this light, individuals, communities, and federal agencies have produced a national narrative of quarantine, contagion, surveillance, and biological threat that undermines public health safety and national progress. This perception of HIV/AIDS – which has been reinforced through public health law and rhetoric, federal departments and agencies, by individuals, and by the HIV/AIDS community itself – has had long-standing negative impacts on many people living with HIV/AIDS (PLWHA). According to the National HIV/AIDS Strategy (NHAS), which was signed into law on July 13, 2010 by President Obama, since the official onset of the epidemic in 1981, “over 575,000 Americans have lost their lives to AIDS and more than 56,000 people in the United States have become infected with HIV each year. Currently, there are more than 1.1 million Americans living with HIV. Moreover, almost half of all Americans know someone living with HIV.” These statistics (while perhaps the pedestrian pieces of information used in discussions and policies regarding HIV/AIDS) are staggering, and they should give us pause as we think more critically about public health law and the individuals and communities it is supposed to serve.

1 Of course, human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) are two separate illnesses. And, this distinction is critical for multiple reasons, least of which includes previously differential treatment and service under Medicaid and Medicare regulations under the Americans With Disabilities Act (ADA) before the Supreme Court’s upholding of the Patient Protection and Affordable Care Act (ACA). Throughout this paper, however, HIV and AIDS will often be referred to synonymously to represent parallel and overlapping stigmas, practices of marginalization and disrespect, and an aggressive politics of disgust which attacks PLWHA.
2 http://www.whitehouse.gov/administration/eop/onap/nhas
Unfortunately, though, these numbers are just the tip of the iceberg. Statistics of national HIV/AIDS mortality, while humbling, are just one dimension of the negative and harmful consequences our public health standards, regulations and the HIV/AIDS narrative have had on PLWHA and their friends and families. Upon deeper inspection, HIV/AIDS data reveals that the disease has progressed to disproportionately impact particular locations and populations “at high risk for HIV infection” (NHAS 8). One of the most disproportionately impacted “target populations” includes gay men – or men who have sex with men (“MSM” in clinical terms—which includes both gay and bisexual men). This community, which has always been the “face of the epidemic” to mainstream media and individuals, comprises only “2 percent of the U.S. population, but 53 percent of new infections” (NHAS 11). Additionally, minority communities have also bared a disproportionate brunt of the HIV/AIDS burden. According to the CDC, “Black men and women represent only 13 percent of the population, but account for 46% of people living with HIV.” Moreover, “the rate of new AIDS diagnoses among Latino men is three times that of White men, and the rate among Latinas is five times that of White women”, and the rate of HIV/AIDS infection among Latino MSM is even greater (NHAS 11). Furthermore, injection drug users (IDUs) – who represent the other major face of the epidemic besides gay and bisexual men – are also disproportionately negatively affected by HIV/AIDS. While there are an estimated 1 million IDUs nationwide, the CDC reports that “injection drug use accounts for approximately 16 percent of new HIV infections in the United States” (NHAS 11).
As is clearly evident, HIV/AIDS no longer affects just white gay males—the community widely claimed and viewed to be the progenitors of the disease. Rather, it has expanded its debilitating reach into the communities of minorities, women, and other social groups facing preexisting stigma and discrimination, and it continues to do so at an alarming and disproportionate rate. Unfortunately, this data still does not fully represent the disease’s impact on our nation and its citizens. The rest of the picture, and a major focus of this project moving forward, has to do with the social ramifications that result as a consequence of being defined as a “diseased” or “target population” that is particularly “vulnerable” to infection (Schneider and Ingram 334). What we lack is a more comprehensive grasp of the stigma, practices of marginalization and disrespect that hold intact and exacerbate the national narrative of “us” versus “them” (which is maintained via numerous binaries, including, but not limited to: dichotomies based on gender, race, sexual orientation, socioeconomic status, healthy/unhealthy, able/disabled, valued/resented). What we are left missing is the untold narrative, a narrative which reveals the ways in which HIV/AIDS has been continually (re)framed since its inception as a convenient excuse for justifying the deep-seated prejudices, discriminatory ideologies and practices of the largely hegemonic, patriarchal state (aka a nation that has largely been run and controlled by heterosexual, socioeconomically privileged white males in their interest) against undesirable “Others” (meaning racial/gender/sexual orientation minorities) as a means of control and power contestation.
Granted this, the question becomes: what does this story tell us? And, then: where do we go from here? For years, many notable scholars, organizations and citizens – both within and outside of the HIV/AIDS community (meaning PLWHA and their friends and families) – have begun to unravel this hidden narrative. Notable individuals such as Ronald Beyer and Gregory Herek (HIV/AIDS epidemic and stigma scholars) and Jonathan Mann (director of the World Health Organization’s Global Program on AIDS) have discussed at length and in great detail the societal, public policy, and public health consequences of leaving this story out of the equation. Herek, exemplifying this fact, writes in his essay *An Epidemic of Stigma: Public Reactions to AIDS*:

> [u]ltimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV or AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings (Herek and Glunt 1988, 465)

Herek continues on in his essay to assert that “with the rise of…increasingly systematic state action to prevent and control infectious disease, the stigmatization of particular races and classes [has] become a consistent byproduct of efforts to intervene” (Herek and Glunt 1988, 465). Through both of these insightful comments, Herek moves beyond traditional HIV/AIDS discourse as a simplified numbers game – crunching the statistics of annual morbidity and mortality to assess our public health status as a nation and whether or not we’ll “make it” (be able to keep more citizens alive than not) – to an intersectional analysis of the public health and societal consequences disease stigma plays in our nation’s social hierarchy, state conquests for domination, and power-relations.
Mann, additionally underscoring the significance of stigma and problematic mainstream views of the epidemic, claims in his Declaration of Commitment (which was made at a UN General Assembly Special Session on HIV/AIDS) that “stigma and the social and political unwillingness to face the epidemic…[are] as central to the global AIDS challenge as the disease itself” (Beyer 2008, 465). Through his claim in the Declaration, Mann posits HIV/AIDS stigma and discrimination as forces that directly tie to efforts to protect human rights and dignity, and that we need to address this issue with equal emphasis and urgency in our collective struggle to “end the epidemic.” For Mann, the denial of inalienable human rights and dignity is directly related to Herek’s claim of the social inequality that results from HIV/AIDS stigma and discrimination, and is a issue of critical importance in our collective struggle against HIV/AIDS.

Herek and Mann’s comments above beg us to think harder and deeper about practices and processes of HIV/AIDS stigma and discrimination and the social ideologies, prejudices, and institutions that continue to support and maintain them in our daily lives. More broadly, they demand a deeper look into the role social pathologies play in power-relations, and the tangible consequences violations of human dignity and respect have on the lives of “targeted” individuals, communities, and public health writ large. These are the questions that get to the heart of the hidden HIV/AIDS narrative. Questions about social inequality and the denial of mutual respect for one another as human beings – which I argue are bolstered and maintained by public health law, policy, and institutions – need to be asked (and hopefully
answered) if we are to ever accurately and comprehensively assess the real status of American public health. The vitality of our nation, which in large part includes the physical and emotional wellbeing of its citizens, is a necessary component to our aspirations of national progress and survival.

Granted the overwhelmingly enormous task at hand, I will provide and analyze examples of public health law, policies, and institutions as an attempt to contribute to this vital endeavor. Plumbing federal health law and policy, discourse from national health organizations (e.g. the CDC and HHS), and community initiatives originating both within and outside of the HIV/AIDS community, I will continue in the heart of prior efforts made by scholars and citizens alike to fully unravel this hidden HIV/AIDS narrative. Specifically, I hope to lay bare the mal consequences that the insidious practices of stigmatization and marginalization have on “particularly at-risk,” “vulnerable,” “target” citizens and populations, as a means of a truthful and naked assessment of our public health status, and, more broadly, our progress as a nation.

Chapter one will begin this project by outlining the concept of social problems and its relation to the national HIV/AIDS narrative. This analysis will pool from the insights of scholars such as Murray Edelman and Deborah Stone into the nature of politics. What we glean from these scholars is that the HIV/AIDS narrative has been strategically crafted argument that serves an ideological function. This purpose has been to maintain status quo power relations—largely to the benefit of those perceived to be “healthy” and “valuable,” at the expense of further marginalizing groups already
facing pre-existing stigmas (aka the “target populations” of HIV/AIDS disease and surveillance). Until we understand this fact, we will be left without a possible solution for effectively ending the epidemic.

Chapter two will build on the descriptions of these theories as they relate to public health law, policy and discourse. Through an intersectional lens, this project seeks to discern and highlight the overlapping social pathologies, practices and identities that serve to (re)marginalize and (re)stigmatize the HIV/AIDS community, as well as threaten our public health and impede our progress as a nation. Through practical examples of health legislation and discourse, I will provide a grounded analysis of mutual respect and a politics of disgust that simultaneously and cooperatively imbed the national HIV/AIDS narrative, and serve to disenfranchise PLWHA as citizens and political individuals. Importantly, I argue that it is not just mainstream institutions and norms which are enacting stigma upon the HIV/AIDS community. Rather, I claim that indigenous leaders from HIV/AIDS minority communities can and do participate in this process as well, as they come to hold positions of power and assimilate to mainstream norms and values. Critically, this form of in-group marginalization (if you will) is a key proponent to the successes the HIV/AIDS national narrative has had in effectively framing and policing the epidemic in its efforts to maintain status quo power relations.

Chapter three will develop my notion of mutual respect as both a posture and practice towards more compassionate public health legislation and deliberative practices. Through an alternative political appeal to the notion of mutual respect, I
argue that it can serve as a social and policy solution to the ongoing HIV/AIDS epidemic. This argument centers on the reconstruction of respect from “the margins”—that is, from the viewpoint of those who are currently labeled and outcast as “target populations” for HIV/AIDS contraction and social risk, and who are most severely disadvantaged from the epidemic. Hoping to contribute to the efforts of those who have already recognized that the elimination of stigma and discrimination is an essential part of ending the epidemic, I believe the notion of mutual respect presented henceforth can serve as a tool towards achieving the social equality and inclusion that our nation aspires to.

In conclusion, I assert that further dismantling of current power dynamics and social prejudices is a necessary step forward for America as a nation, and that this project will further prior attempts to expose the hidden HIV/AIDS narrative and agenda that have continued to impede public health goals and priorities since the onset of the epidemic. What we do know is that it will take the concerted and continued efforts of all Americans in order to finally make good on America’s promise of an inclusive and egalitarian democracy for all, regardless of one’s social identity or upbringings. While this has been and will continue to be an arduous and timely endeavor, I believe we must ask more of ourselves and of our nation as the international standard-bearer of democracy.
Chapter 1: “Us” versus “Them” and the Hidden Agenda

In order to comprehend the hidden agenda of the national HIV/AIDS narrative, analysis henceforth will hinge upon Murray Edelman’s depiction of what social problems are, how they come to be defined and enter discourse, and the political consequences they hold for respective individuals and communities affected by the problem and involved in the solution-finding process. In his foundational book *Constructing the Political Spectacle*, Edelman defines social problems as ideological constructions which are inherently political. Edelman writes in further explanation that problems come into discourse and therefore into existence as reinforcements of ideologies, not simply because they are there or because they are important for wellbeing. They signify who are valued and useful and who are resented or inadequate, which actions will be rewarded and which penalized (Edelman 12)

From Edelman’s definition of social problems, we glean that social issues are constructed as “problems” as a means of defining the contours of the social world around a particular topic. As such, who defines the problem, when and if the problem enters national discourse, and the actors or interest groups that are located respectively along the valued/resented, useful/inadequate binaries necessarily bounds the context of the problem to a specific era and set of ideologies. Issues that are elevated to national prominence become “social problems” in order to further the ideological interests of those who define the problem as such, and the symbols, arguments, and judgments used to carry out this work are bound within the time period and social context.

Consequently, the individuals and interest groups who hold a stake in solving the problem – aka the “stakeholders” – are dependent upon how, when and why the
problem is defined, and are subject to fluctuate and be redefined as the problem and the power structure of society evolve. Edelman further explains that, central to this analysis, then, “is the diversity of meanings inherent in every social problem, stemming from the range of concerns of different groups, each eager to pursue courses of action and call them solutions” (Edelman 15). What we glean from Edelman’s statement is that while social problems are defined by a particular group with a respective set of ideologies and values, that within each problem, there exists an array of affected individuals and communities (e.g. interest groups) which hold their own set of concerns and ideologies, which they support and pursue through problem-solving efforts. Thus, for each group, the substance and consequences of the “problem” necessarily vary because competing claimants or groups define the issue differently (Edelman 15).

Applying Edelman’s theory of social problems to the American HIV/AIDS epidemic informs our understanding of how the issue initially entered national discourse, who the current stakeholders are, and how the problem has evolved to affect legislation and public health in a crucial way. As stated in the introduction, the national HIV/AIDS narrative began as an indictment of white gay males and their alternative sexual practices that brought this “plague” to our nation. The problem was initially defined by mainstream, heterosexual elites in positions of power to bring awareness to the perceived biological threat born from these resented “Others” and their deviant ways. This narrative constructed the HIV/AIDS epidemic as a public health threat, creating a bifurcated system that located heterosexuals as healthy and
valuable, and homosexuals as infected (or vulnerable to infection, and at-risk for infecting the rest of the nation), thus threatening national security and public health. The policy agenda set forth and pursued over the following years was narrowly created by those who were already in positions of power, and whose authority and status was additionally bolstered through the moral judgments and ideological claims proffered by the definers of the social problem.

Hence, it is evident how the construction of the HIV/AIDS epidemic as a national social problem worked within prevailing ideological confines and national values to further the interests of the status quo power structure. That is, heterosexual elite white males defined the problem as a gay illness (AIDS was initially termed “Gay Related Immune Deficiency,” or GRID), assigning moral worth and executive authority to themselves and the healthy heterosexual population, while marginalizing and discriminating against the sick and diseased homosexual community. In fact, not only have PLWHA been portrayed as resented and threatening the vitality of the body politic, but what they have had to say about the HIV/AIDS epidemic has been prohibited from any spot in national discourse for some time. As HIV/AIDS community leaders have risen to positions of relatively more power, their views and opinions have achieved marginally more recognition; however, the content of their messages, and their ability to participate in and affect the policymaking process have remained confined by the power structure within which the HIV/AIDS narrative has been bounded. This realization gets at the heart of Edelman’s depiction of social
problems as inherently political ideological constructions that work to further the power interests of the prevailing power structure.

As the epidemic has evolved over the years, however, expanding its grasp into various new communities (including the heterosexual community, which was previously thought to be “safe” from infection) and attaining increasingly perilous mortality and morbidity numbers, the contours of the social world outlined by the problem have shifted. New stakeholders such as IDUs and minority communities (due to their disproportionate share of the HIV/AIDS burden) have been identified and incorporated into the problem, and the goals for finding a solution to end the epidemic have shifted primarily from mediating the mal consequences of a biological virus from infecting the national body, to containing a heightened social risk that threatens the progress and survival of our nation.

Drawing from Edelman’s insight of social problems, we understand that the stakes each affected group has in the HIV/AIDS problem have concomitantly evolved with the national narrative. Marginal racial groups and IDUs have become increasingly cognizant of the rising infection and mortality rates within their populations, and responsible community organizations have refocused their efforts to support the various solutions that they believe can stem these alarming statistics and reverse the trend. Heterosexuals living with HIV/AIDS have formed coalitions with other HIV/AIDS advocacy and support organizations, as the dichotomy between healthy and unhealthy, valued and resented has moved beyond the prevailing straight/gay binary. Community leaders arising from underserved populations have
risen to newfound positions of power, which has granted them marginally better status and more authority in (re)defining the problem and offering potential solutions. The advancement of some marginal community members to positions of authority (relative to mainstream authority figures) has consequently transformed the national HIV/AIDS policy agenda. However, as we will come to see, the marginal gains that have been made by community leaders of previously ostracized and stigmatized groups have often worked to reinforce mainstream ideologies and visions of “progress,” whether the respective community leaders were doing so consciously or not. And, relationships between competing interest groups have developed to accommodate newfound alliances between communities with likeminded visions of progress, and whose fate has become inextricably linked to the eradication of the HIV/AIDS plague.

What we glean from above is that Edelman’s insight into the construction of social problems significantly informs our understanding of the national HIV/AIDS narrative. Edelman’s description aptly reveals who the stakeholders have been in the HIV/AIDS epidemic, how new stakeholders came into play, and why the problem entered national discourse in the first place. Not only does it serve to define the HIV/AIDS epidemic as a problem constructed by the heterosexual white majority to further stigmatize and marginalize sexual “deviants,” justifying many pre-existing prejudices against homosexuals in the process, but it also informs our understanding of the policy agenda set forth by mainstream organizations and processes to “solve” the crisis. However, what Edelman leaves us left wanting is the substance of the problem at hand. Edelman’s work serves to outline the structure of the social problem,
yet we are left still lacking the particular processes of discrimination and marginalization that have come to be prominent social consequences of the epidemic.

The narrative of containment and surveillance issued forth by mainstream claimants has worked largely to conceal the opinions and contributions of HIV/AIDS communities over the years in the formation of public health legislation. By establishing themselves as the definers of the epidemic – and, thus, the figures with the authority and knowledge to resolve the problem – mainstream political elites have downplayed and hidden the values and inputs of indigenous community leaders in ending the epidemic and returning our national body to a “healthy,” “safe” status once again in the national narrative.

This process of concealment has resulted in what I call the hidden HIV/AIDS narrative—that is, the history of views and contributions made to public health law and regulation around the HIV/AIDS epidemic from the point of view of the targeted HIV/AIDS communities, which has gone largely unnoticed due to the policy construction of mainstream claimants. This narrative emerges from the hidden agenda of public health elites and authority figures—that is, to maintain or improve status quo power relations. Processes of marginalization and stigmatization – carried out through practices such as assigning moral value and judgment upon those who are known to have HIV/AIDS, and consequently “targeting” perceived “vulnerable populations (aka PLWHA and those whose sexual or social behaviors puts them “at-risk” for HIV/AIDS contraction) – have been buried in the larger national narrative of needing to contain and control the virus. This narrative has remained “hidden” from public
view and discourse under the guise of a pertinent health crisis due to the policy direction and formation from policy and public health elites—for, to reveal this narrative would endanger the status quo power relations. Bringing national attention to the ways in which public health law has ignored the concerns and contributions of indigenous HIV/AIDS leaders and organizations would expose and jeopardize the hidden agenda of HIV/AIDS legislation and political elites, who have worked to sustain the containment and surveillance of these “resented” individuals and communities.

However, I contend that it is not only in the public’s interest, but that it is also necessary to exploit the underlying agenda of the HIV/AIDS narrative in order for the nation to move forward with resolving ourselves of this “crisis.” Therefore, the primary focus of this project henceforth will be to unravel this hidden narrative from the mainstream HIV/AIDS public health narrative. As mentioned above, previous political and public health authority figures such as Jonathan Mann have claimed that the stakes of the HIV/AIDS epidemic have evolved, such that the stigma and discrimination resulting from the identification of individuals living with the virus have become as central to the epidemic as the disease itself. Revealing the hidden arguments and reasoning behind the direction and content of public health legislation regarding HIV/AIDS helps to illuminate, and may help to resolve, the surface conflicts surrounding the health panic.

Moving forward, this project will attempt to address these processes through multiple lenses of analysis. Through an intersectional lens, this analysis will focus on
the power structures of American society which not only function in the traditional
top-down dynamic – in which dominant groups enact power over disadvantaged
groups – but will additionally address the ways in which underserved communities
and interests groups have contributed to, accommodated, and resisted mainstream
values and ideologies imbedded in the national HIV/AIDS narrative.

A central mechanism in the maintenance of privilege and subordination in this
context is a politics of disgust, which posits the healthy/unhealthy binary within a
moral context in which the former is perceived as valued, and the latter as resented.
This binary thus involves individuals and communities in a reciprocal process of
identity formation, in which they both self-define and are ascribed social attributes and
moral values by other citizens. Ange-Marie Hancock, in her work *The Politics of
Disgust*, explains this process further. In her description of the politics of disgust,
Hancock asserts that one’s public identity (in this case, that of respective stakeholders
engaged in HIV/AIDS debate and policymaking) is conditioned, ”not simply by one’s
own speech and action but also by others’ perception, interpretation, and
manipulation—particularly for those citizens who lack political equality (Hancock 4).
This is to say that PLWHA and the greater HIV/AIDS community (meaning those
who have significant others, friends, and family who are living with HIV/AIDS) form
their own identities, and that this identity is also shaped and confined by the social
contours of the world and the context in which they find themselves. This reciprocal
process of identity formation is “conditioned,” as Hancock says, by the environment in
which one grows up and lives—including one’s geography, demography, and the era
in which one lives. These factors, or what I will come to define as “social pathologies,” further inform our analysis of the HIV/AIDS narrative, providing additional insight into how, why, and by whom HIV/AIDS policy agenda-setting is made and how public health law works to differentially affect individuals and communities based upon their respective identities.

Through the lens of a politics of disgust, analysis of public health law will henceforth show that stakeholders’ identities located across the healthy/sick, valued/resented binaries hold tangible political consequences for their ability to engage in deliberative democratic processes and practices, as well as their ability to receive the forms of healthcare they may need. Specifically, my analysis will rest upon the NHAS and other foundational HIV/AIDS surveillance mechanisms as perpetually challenging our public health objectives. Public health law serves as one example of how one’s human body maps onto their social body, resulting in respectively positive or negative outcomes for the individual. If the individual is perceived to be physically healthy, they are thus defined as more able to contribute and thus “valuable” to the body politics. Concurrently, if an individual is perceived to be “sick” (as PLWHA are), they are judged to be less valuable and sometimes even “resented,” as their physical health is viewed as a potential threat to the physical and social health of the national body.

Through the lens of target populations, this analysis will examine how and why populations come to be perceived as “at-risk” for infection, and the consequences this has on their ability to engage in a deliberative democracy. As we will see, the
designation of particular populations as being “targeted” by the state via prevailing public health law and practices currently functions to further marginalize individuals and communities that are already targeted by dominant groups and interests – through pre-existing stigmas and practices of discrimination – further enfeebling them as political actors in deliberative processes. Within the national HIV/AIDS narrative, we are left asking: by whom or what are these populations being targeted? Does this label refer to the HIV/AIDS virus, state surveillance systems and mechanisms of control, or both? Are these “target populations” targeted solely by mainstream claimants, or are there also underlying practices of separation that further isolate already disadvantaged community members? This analysis shall attend to these questions, and I shall argue that the assignation of the label “target populations” to particular communities and social identities works within a politics of disgust and disrespect to further entrench deep-seated prejudices, maintain status quo power relations, and reinforce the national HIV/AIDS narrative as an agenda of “Us” versus “Them.”

Finally, through the lens of mutual respect, this analysis will examine public health legislation and practices– originating from both mainstream and in-group (e.g. from the HIV/AIDS community) institutions and organizations – as processes of disrespect which additionally stigmatize and marginalize PLWHA, and those perceived to be “particularly vulnerable” for HIV/AIDS infection. This lens of mutual respect will hinge upon the stigma of (both perceived and actual) difference, and the political consequences moral judgments accompanying the healthy/sick, valued/resented binaries hold for various political actors. Specifically, this analysis
will reveal that through (re)definition of the HIV/AIDS problem, our social world is bound within a context in which vulnerability is already unequally distributed in political life (Disability as Vulnerability article 7). Furthermore, because our world is already “structured to respond to some people’s vulnerabilities better than others…risk and exposure [are] manifested in uneven ways”, further exacerbating social stratifications and cementing status quo power relations (Disability as Vulnerability 7).

In order to overcome these insidious practices and political and social obstacles, this analysis will discuss alternative conceptions of vulnerability, progress, and mutual respect as a means of (re)framing the HIV/AIDS debate in a more compassionate light.

This work will rest upon a final contribution of Edelman’s analysis of the public construction of social problems. Concluding his argument about social dilemmas, Edelman claims that politics must change before our understanding of the problem changes. This means that how we view politics – as a means of accomplishing particular objectices (these “objectives” being, in a broad sense, social order and progress) – must change in order for us to perceive a problem in a different light. In the case of the HIV/AIDS dilemma, if we continue to ground our understanding of the epidemic in the narrative portrayed by mainstream political and public health elites and authority figures, then we can expect to achieve the same results we have been getting—further stigmatization and marginalization of previously ostracized groups and community members, and a latent epidemic that continues to negatively affect individuals’ access to health care. However, if we alter our
conception of politics to be a means of deriving alternative understandings of the epidemic, and if we continue to deconstruct the national narrative in order to expose the hidden agenda of mainstream claimants in constructing the HIV/AIDS panic, then perhaps we can transform our perception of HIV/AIDS politics in the hope of formulating new ideas for solutions to ending the epidemic.

Public policy scholar Deborah Stone, in her work *Policy Paradox: The Art of Political Decision Making*, informs the work presented to us by this challenge. In her description of public policy, Stone argues that heretofore the fields of political science, public administration, law and policy analysis have shared a common mission of rescuing public policy from the irrationalities and indignities of politics, hoping to make policy instead with rational, analytical, and scientific methods (Stone 6).

This perception of politics – as a mechanism for meting out the “irrationalities” of political life (meaning the confusion, suffering, and disappointment that results from politics and its consequent differential distribution of political and social resources) – has driven policymakers to view legislation as a means of rational analysis and resolution to the social problems we face. Stone defines this perception of politics as “the rationality project,” in which legislators and authority figures believe they can solve social dilemmas through objective, scientific observation and problem-solving efforts. This rationality project hinges upon the understanding that politics functions like the marketplace, with rational individual actors analyzing political transactions through the lens of cost-benefit analysis, always seeking the path of most benefit with the least cost to them.

Stone aptly points out, however, that this perception of public policy misconstrues the nature of politics and the essence of policy making in political
communities. Instead of viewing politics as a marketplace full of rational actors and cost-benefit decisions, Stone argues that the central tenet of politics is the struggle over ideas (Stone 11). The contestation over ideas and shared meanings motivates “people to action and [melds] individual striving into collective action” (Stone 11). Stone correctly argues that politics is made messy by the relationships and emotional bonds we hold to our families, loved ones, and communities, and that these factors make the rationality project nothing less than an impossible dream.

Thus, Stone argues that a more accurate understanding of politics lies in how we understand political reasoning. Through the lens of politics as a struggle over ideas, Stone claims that “[p]olitical reasoning is metaphor-making and category-making, but not just for beauty’s sake or for insight’s sake. It is strategic portrayal for persuasion’s sake, and ultimately for policy’s sake” (Stone 9). In further explanation, Stone claims that policy is “a creature of politics itself; it is strategically crafted argument, designed to create ambiguities and paradoxes to resolve them in a particular direction” (Stone 7). This is to say that because public policy is informed and directed by this contestation over ideas, we can understand that policymakers construct legislation in order to validate their social framework.

Stone’s analysis of politics and public policy fits well with Edelman’s notion of social problems as ideological constructions designed to further the interests of policy makers. This alternative understanding of public policy and political reasoning informs the HIV/AIDS epidemic and our analysis of public health legislation, in that it transforms our understanding of what politics is and what it hopes to achieve. Public
policy is not a means of problem-solving through rational observation and decision-making. Rather, public policy is a mode of control, through which policymakers strategically construct values, symbols, and categories to further their ideological interests. Viewing the national HIV/AIDS narrative in this light informs our understanding of why and how public health legislation has been created. Moreover, it gets us to the point where we can finally change our understanding of the epidemic. HIV/AIDS has always been a health issue, in that it is a virus that potentially has life-threatening affects for those infected by it. However, the construction of the HIV/AIDS narrative has portrayed the epidemic as a biological threat, putting the national body “at-risk” for infection and thus posing a challenge to national survival.

Acknowledging this, I contend that it is not HIV/AIDS itself, but how it is portrayed and regulated through public health law and policy, that is the political problem. Targeting, stigmatizing and discriminating against PWLHA is founded in a politics of disgust and disrespect, which collaboratively hinder our understanding of the actual problem at hand—that is, that there are thousands of Americans that are not receiving the health care they need or deserve as fellow citizens and human beings.

From the standpoint of Edelman and Stone, the formulation of status quo public health law and policy makes sense in that it has been constructed to serve the interests of the policymakers and authority figures who designed it. However, the problem is that these laws and policies are not able to get us to where we want to go—that is, ending the epidemic and no longer having HIV/AIDS be a national health crisis. In order to get there, we must change our understanding of the HIV/AIDS epidemic, and accept
that public health law and policy as it currently functions in fact perpetuates the health problem. Until we get to the heart of the hidden HIV/AIDS agenda, and until we transform our public health law and policy in order to be more compassionate towards the HIV/AIDS communities, and our fellow citizens in need of health care, we will never be able to resolve ourselves of this problem.
Chapter 2: Discrimination, Disgust and Disrespect in the NHAS

Through efforts seeking to expose the hidden HIV/AIDS narrative and agenda, I have turned to the National HIV/AIDS Strategy (NHAS) as the exemplar of the ways in which public health law employs disrespectful and discriminatory language through the lens of a politics of disgust. The language carried out through federal policy such as the NHAS not only further marginalizes PLWHA, exacerbating the many pre-existing stigmas associated with their positive HIV status, their consequent perceived “threat” to national health, and their deviant sexual practices, but also hinders their ability to receive the healthcare access and services they need and deserve as equal citizens and fellow human beings. As we will come to see, practices of fear-baiting and disrespect – centered around language labeling PLWHA as “particularly vulnerable” and in need of “behavioral interventions,” the construction of a narrative of biological threat and contamination, the targeting of specific populations that are especially “at-risk” for infection and exposure, etc. – pervade the NHAS, and strategically inform the HIV/AIDS policy agenda heading towards the future.

Acknowledging these facts, my deconstruction of NHAS language and policy is by no means an attempt to claim failure or hatred on the part of particular public health officials or HIV/AIDS-related institutions and organizations. Rather, this critique is being made in an effort to help shed light on the ways in which public health law and policies continue to disrespect and marginalize the HIV/AIDS community through institutional processes of exclusion and differential treatment.
Through the construction and employment of language grounded in a politics that poses PLWHA as “disgusting,” resented/threatening, and “sick,” status quo public health law results in a health care system in which individuals and communities do not receive the access to health care services they need, are often unable to have their voices or concerns heard by public health officials, are afraid to or do not know how to learn their serostatus, and when they are able to access HIV/AIDS prevention information or treatment, are left overcoming social and policy barriers (e.g. HIV/AIDS-related stigma, discrimination, lack of access to the quantity and quality of health care services and medication they need, lack of access to housing and/or transportation to health care providers, and so forth) which act as major disincentives and cripple their efforts to stay on stable treatment regimens, prevent HIV transmission to others, and/or remain healthy citizens.

Moreover, as we will come to see, the NHAS does not “get everything wrong.” In formulating the NHAS, policymakers critically recognize and speak to a variety of issues that function within the type of comprehensive framework necessary for a healthier, more inclusive, more egalitarian health care system. Important issues and barriers to HIV/AIDS policy (such as waiting lists and limitations on lifesaving medications, the burden of co-occurring conditions on PLWHA, as well as the disproportionately high rates of poverty, unemployment, domestic violence, hunger, lack of access to transportation and stable housing, etc. compared to individuals without HIV/AIDS) are discussed as critical impediments to lowering the rate of HIV transmission, occurrence, and the differential impact of HIV/AIDS on particular
communities. (NHAS 21 – 31). Moreover, the NHAS renews efforts to ensure that those who choose to be sexually active have the information necessary to protect themselves and practice safe sex, to reduce disparities in health care access among differentially affected communities, and to reduce stigma and discrimination against PLWHA (NHAS 20, 31, 35 respectively). While some of these commitments can only be taken at face value, as they are either encumbered by the same forms of disrespectful language that pervades the rest of the NHAS and the national HIV/AIDS narrative, or because they fall back to the type of ideology consistent with Deborah Stone’s notion of politics as a “rationality project,” simply being included for discussion in the document ought to be taken as a positive step forward for HIV/AIDS policy and our nation’s healthcare future.

Granted this, much of the NHAS remains embedded in problematic language that functions as an impediment towards more compassionate HIV/AIDS policy, more inclusive and respectful deliberative practices and processes, and a healthier nation. This chapter will break the NHAS down into several subsections of analysis, focusing on the language of “target populations,” “behavioral interventions,” and the national HIV surveillance system as communicative means which promote and bolster a national HIV/AIDS narrative that is antithetical to our nation’s national health objectives. Through the deconstruction of these various language tools, I hope to expose the ways in which public officials construct policy that is disrespectful of PLWHA and poses them within a politics of disgust that nurtures and maintains the impossibility of extending mutual respect to the greater HIV/AIDS community.
Concluding my analysis of NHAS language and policy, I argue that unless we come to perceive HIV/AIDS and “the epidemic” in a more compassionate light, and unless we change the language we employ in public health legislation such as the NHAS to be more respectful of the lives and social realities individuals such as PLWHA face, we will continue to fail the hundreds of thousands of fellow citizens and human beings in need of vital healthcare access and services they deserve, and impede our national progress towards a more inclusive, egalitarian democracy.

Target Populations

Laying the groundwork for target population theory, Anne Schneider and Helen Ingram, in their article *Social Construction of Target Populations: Implications for Politics and Policy*, define the social construction of target populations as “the cultural characterizations or popular images of the persons or groups whose behavior and well-being are affected by public policy” (Schneider and Ingram 334). Schneider and Ingram further explain that these characterizations “are normative and evaluative, portraying groups in positive or negative terms through symbolic language, metaphors, and stories” (Schneider and Ingram 334). From Schneider and Ingram’s definition, we can deduce that in accordance with Edelman and Stone’s notion of politics, language and symbols are used to socially construct group identities (in our case, the HIV/AIDS community and PLWHA being the “target population” of concern), shaping both the policy agenda and the design of policy itself in order to carry out certain government objectives (Schneider and Ingram 334).
In further explanation of Schneider and Ingram’s theory, we can deduce that target populations are constructed by policymakers with either positive or negative attributes, meaning that to be a “target population” does not necessarily equate to negative sociopolitical outcomes (i.e. denial of equal citizenship status, punitive/punishment-oriented policies for stereotypical group actions or characteristics, differential treatment under the law, and so forth). Schneider and Ingram emphasize this point, contending that there are “strong pressures for public officials to provide beneficial policy to powerful, positively constructed target populations and to devise punitive, punishment-oriented policy for negatively constructed groups” (Schneider and Ingram 334). In our case of HIV/AIDS public health law, this definition of target populations maps perfectly onto the construction of the healthy/sick, resented/valued binaries, as certain communities (e.g. whites, heterosexuals, the socioeconomically privileged, and individuals who do not use drugs) have continued to receive the benefits of greater access to robust, quality healthcare and a lack of historical stigma and discrimination against their sexual/social orientations and identities, while PLWHA and those who are portrayed as engaging in “risk behaviors” and as being “at-risk” for HIV infection have faced significantly less access to health care services, continued HIV- and AIDS-related stigma and discrimination, and an inability to fully and meaningfully participate in and contribute to HIV/AIDS deliberative processes, resulting in their currently marginalized and unequal status as citizens.
The “strong pressures” influencing policymakers’ decisions can be derived from government’s objective of maintaining or furthering status quo power-relations, resulting in the provision of benefits through policy to advantaged groups to maintain their hierarchy over relatively disadvantaged groups, while penalizing the actions and identities of communities and individuals perceived to be threatening to the national power structure. Importantly, we must recognize the fact that these pressures are dependent upon the social issue and its historical national context. Analogous to the situation of stakeholders for a given social issue or problem previously mentioned, the construction of a target population is subject to fluctuate and be redefined as the problem and the power structure of society evolve, making for a complex process of identity formation and (re)construction in which the identity and status of target populations shift to accommodate ruling notions and norms to best achieve government objectives from the standpoint of public officials and policymakers.

This fact can be evidenced throughout HIV/AIDS history, as we have seen the composition of target populations evolve at respective points in time. At the onset of the epidemic we saw the construction of the majority of the American public as the “valued” target population, and the consequent construction of white homosexual males as the threatening community that was to be confined and controlled through legislative language and public health policy. As the disease spread to infect new and diverse communities, the symmetry of target populations transformed to include new communities such as IDUs, racial minorities, socioeconomic underclasses, and the transfer of some previously “valued” heterosexual white males to a relatively more
disadvantaged status, concomitant with the emergence of MSM as a newly recognized social identity. Furthermore, as community leaders within disadvantaged and underserved populations (e.g. racial minority HIV/AIDS communities) have assimilated to hegemonic norms and values, incorporating the socially stratifying binaries into their own ideologies and actions – demarcating certain individuals as “healthy” and “valuable” citizens and others as “sick,” threatening, and undeserving – we have seen the incorporation of some minority elites from the HIV/AIDS community into target populations that have positive attributes and connotations, and which receive benefits through public health policy and legislation.

Through Schneider and Ingram’s description of target populations, upon closer inspection we see that this lens conditions much of the NHAS language regarding HIV/AIDS communities. The prominent bifurcation between healthy citizens and particularly “vulnerable” communities “at-risk” for both infection and disease transmission constructs the boundaries within which the national HIV/AIDS narrative is grounded. This narrative promotes the protection and safeguarding of “healthy” populations that are yet to be infected, while reemphasizing national focus and targeting efforts towards controlling “sick” populations in order to quarantine and stem the disease. As the NHAS states under its recommended actions for reducing new HIV infections, one of our top priorities should be to “target high-risk populations,” with federal agencies developing new mechanisms “ensuring that grant funding to State and local health departments and community-based organizations is
based on the epidemiological profile within the jurisdiction” (NHAS 15). Specifically, the NHAS lays out the “high-risk populations” which need to be targeted: gay and bisexual men and transgender individuals, Black Americans, Latino Americans, and substance users (NHAS 15). These populations map onto the current sociopolitical bifurcation between healthy/sick, valuable/resented populations which we see today in the HIV/AIDS epidemic, importing notions of which communities are in need of our help and which communities should be targeted for disease prevention.

Granted, that these target populations have disproportionate rates of HIV infection and transmission is not untrue. Moreover, the fact that these communities are in need of our attention and HIV prevention efforts is clear. However, where this language becomes problematic is how we describe these facts, and how we portray the current HIV/AIDS epidemic with regard to these citizens. Through language that “targets” these individuals for refocused attention and efforts, communities that are disproportionately affected by HIV/AIDS come to be viewed as in need of special attention and unequal treatment. Instead of stating that all PLWHA and communities should be educated with prevention and treatment information, and that all citizens should have access to the type of health care services that will ensure healthy lives, the NHAS marks these target populations as separate from the rest of the national body, alluding to notions of differential treatment and their need of being saved from their “vulnerable,” “at-risk” status. Construed by binaries that portray PLWHA and the HIV/AIDS community as sick, undeserving, and threatening our national health, these
communities are confined within a narrative that prevents any hope of their attaining equal status and treatment in our current health care system.

In working towards a more inclusive, egalitarian, compassionate health care system, health policy language needs to be modified to detangle ourselves from this mess. Currently, language employed in the NHAS serves to identify where citizens are located along these aforementioned sociopolitical binaries, instruct individuals and communities of their status as citizens, and, consequently, inform them of the respective types of care and services that they deserve and should receive. More compassionate health care policy and legislation would do no such thing. Rather, language in such policy would emphasize the fact that our nation values the health and safety of all citizens equally, and that all efforts should be made to ensure this reality. Communities currently targeted by prevention and treatment efforts would be removed of this differentiating status, and any notions of “special treatment” that they are currently encumbered by. More compassionate health care policy would promote access to the same type of robust, high-quality health care services that are currently only available to small segments of our population. More compassionate health care policy would promote the health and vitality of all our nation’s citizens, with no need of epidemiologically profiling individuals and populations to evaluate their respective level of need and care. Such “profiling” warrants the maintenance of differential treatment and access, ensuring the failure our nation’s espoused objectives of achieving a healthier nation and future and one day “ending the epidemic.”
Schneider and Ingram, in summary of their description of target populations and their implications for politics and policy, assert that the theory of the construction of target populations “helps explain why some groups are advantaged more than others…and how policy designs can reinforce or alter such advantages” (Schneider and Ingram 334). According to Schneider and Ingram, the “agenda, tools, and rationales of policy import messages to target population’s that inform them of their status as citizens and how they and people like them are likely to be treated by government” (Schneider and Ingram 340). These messages become internalized by citizens through both the observation of politics and media coverage and personal experiences with public policy, letting citizens know whether they will be viewed as “clients” by government or whether they will be treated as “objects” (Schneider and Ingram 340-341). From Schneider and Ingram we glean that public policy not only impacts the lives of individuals and communities through social benefits and/or hindrances, but also shapes their understanding of their status as a citizen.

Through analysis of the NHAS’s policy of targeting specific populations for HIV/AIDS surveillance and intervention, I posit that HIV/AIDS public health legislation’s impact on the lives of individuals and communities is multiple. Not only does it inform our understanding of which citizens are to be considered “valuable,” which not, and why respective groups should receive certain sociopolitical benefits or detriments from public policy, but it also informs individual notions of why particular groups are treated differently than others through the eye of the law, whether or not they will receive the same opportunities as others in their life pursuits, and whether or
not they will be treated as “clients” or “objects” by governmental actors and
institutions. Developing my notion of mutual respect in the following chapter, I argue
that more comprehensive, compassionate HIV/AIDS public health agenda and policy
should treat political stakeholders as neither “clients” nor “objects” of the government,
but, rather, as equal participating citizens who hold a stake in the present and future
state of our nation. Granted that media coverage, politics, and individual experiences
dealing with public policy have such a powerful impact on the social perceptions and
realities of individuals, in order to achieve a more inclusive and egalitarian health care
system, we must strive for language and policies that reflect and reemphasize our
goals towards progress.

**Behavioral Interventions**

Another subtopic of NHAS language deserving our attention is the discussion
of “behavioral interventions” for PLWHA and those “at-risk” for infection (NHAS 16-17).
In accordance with PLWHA and particular racial and socioeconomic populations
being targeted by federal agencies and institutions, the NHAS states that we should
prioritize the dissemination and utilization of behavioral interventions in communities
heavily impact by HIV (NHAS 17). Such “scientifically proven behavioral
interventions,” even though they have “not been proven to reduce HIV
infections…promote responsible sexual behaviors that may lower a person’s risk for
becoming infected with HIV and some have been associated with reducing STIs”
(NHAS 17).
NHAS’s discussion of “behavioral interventions” primarily pulls from the work of Thomas Coates, Linda Richter, and Carlos Caceres in their article *Behavioural strategies to reduce HIV transmission: how to make them better*. Herein, Coates et al define behavioral strategies as:

- those that attempt to delay onset of first intercourse, decrease the number of sexual partners, increase the number of sexual acts that are protected, provide counseling and testing for HIV, encourage adherence to biomedical strategies preventing HIV transmission, decrease sharing of needles and syringes, and decrease substance use (Coates et al 2)

Differentiating behavioral strategies from structural and biomedical strategies, Coates et al continue on to explain that:

- whereas structural strategies seek to change the context that contributes to vulnerability and risk and biomedical interventions block infection or decrease infectiousness, behavioural strategies attempt to motivate behavioural change within individuals and social units by use of a range of…approaches (Coates et al 2)

From these two comments of Coates et al, we glean that behavioral strategies or interventions are a means of reducing HIV infection and transmission through educating about the behaviors that place them “at-risk,” as well as encouraging individuals to reduce the amount and frequency with which they participate in these behaviors.

In and of themselves, the factors that Coates et al list under their definition of “behavioral strategies” do significantly contribute to HIV infection and transmission. Calling attention to these “risk factors” (if you will) is a critical aspect to effectively and comprehensively educating individuals about HIV infection and transmission, and is essential to the type of comprehensive framework we need in working towards a more inclusive, egalitarian, compassionate health care system and public health legislation. However, similar to the topic of target populations, where this language
becomes problematic lays not in the content itself, but how the language is used to promote public health and governmental objectives. Primarily, language regarding “behavioral interventions” in the NHAS falls prone to the notion of what I call “scientific disengagement”; that is, language that is clinical in nature, which many general citizens do not understand and which acts as a disincentive for their continuing education and prevention efforts. Instead of referring to strategies that effectively reduce the chance of HIV infection and transmission, the NHAS employs the language of “behavioral interventions,” which is a complicated, messy, and not-all-that-well understood term.

Furthermore, the use of the term “behavioral interventions” becomes problematic when looked at through the lens of the social identities and the disproportionate impact of HIV/AIDS on particular communities. Because HIV/AIDS primarily affects racial and gender minorities (e.g. African Americans, Latinos, gay/bisexual/transgender individuals), we must remain cognizant of the fact that there already are pre-existing stigmas attached to the identities and behaviors of such individuals and communities. From African Americans (in particular, males) being hypersexual, to Latinos being “dirty,” to gay/bisexual/transgender individuals engaging in sexual behaviors that mainstream individuals may view as extreme, weird, disgusting and so forth, these pre-existing stigmas directly impact the social perceptions, worldviews, actions, and citizenship status of such individuals. Keeping this in mind, I argue that the language of “behavioral interventions” becomes additionally problematic, as it has the potential to come off to PLWHA and others as
an attack on the character and identity of those who become infected or transmit HIV, as well as those portrayed as “at-risk” for HIV/AIDS acquisition (due to its largely unknown definition among the general citizen population).

Concluding their argument, Coates et al correctly assert that multiple “behaviors collectively enhance risk, and they need to be targeted through many levels to achieve the best results” (Coates et al 5). Coates et al continue on to remark that the “right combination of strategies, of course, depends on the profile of the populations engaging in risky activities, among whom HIV is spreading” (Coates et al 5). From these statements, we deduce that Coates et al are strongly in favor of working towards a more comprehensive framework for HIV/AIDS policy. This comprehensive framework would not only recognize that different prevention, education, and treatment strategies work better for some communities than others, but also that a combination of strategies is the most effective and promising method for achieving a healthier nation and one day “ending the epidemic.”

In sum, NHAS’s use of the language of behavioral interventions is problematic on at least two accounts: first, it is language of “scientific disengagement,” and second, it can be viewed as an attack on the individual nature of PLWHA and the greater HIV/AIDS community. These are the two issues that my argument takes up with such language, although I do not discount the fact that others might find “behavioral intervention” language problematic for other reasons. Again, while the actual meaning of behavioral strategies and interventions is not in and of itself problematic – on the contrary, I find the strategies discussed by both the NHAS and
Coates et al to be vital parts of the type of comprehensive framework needed in HIV/AIDS policy in working towards a more inclusive, egalitarian, compassionate health care system – similar to the language of target populations, behavioral interventions becomes problematic due to the nature in which it is employed by policymakers and public officials.

Instead of relying on language that “calls out” and socially demarcates individuals based on their sexual preferences, the number and type of sexual partners one engages with, and their social identity (self-identified or ascribed), I argue that more compassionate HIV/AIDS policy would reemphasize the need to continue to promote HIV/AIDS education, prevention and treatment efforts for all citizens. With the realization that our nation is continually growing more diverse – ethnically, racially, socially, and otherwise – public health legislation needs to devise a more comprehensive framework and strategy moving forward that reflects this reality, and that is able to reach all segments of the population. If HIV/AIDS is an epidemic that truly affects all Americans, as the NHAS claims it does, then we need a health care system and policy agenda that helps all citizens stay healthy on an equal playing field, plain and simple.

**National HIV Surveillance System**

This final subsection of NHAS policy analysis will focus on the use of language regarding HIV surveillance and the National HIV Surveillance System. According to the NHAS, the “quality of information that we have to understand the
epidemic we face and how it is changing depends on having an effective HIV surveillance system” (NHAS 18). The primary source of data used to monitor the epidemic in the U.S. is the “National HIV Surveillance System,” which is used “extensively to target and evaluate HIV prevention and care programs” (NHAS 18). This database pulls information from providers, laboratories, and State and local health departments to “coordinate accurate, complete and timely reporting” and to track the progression of the disease among communities and individuals (NHAS 18). While this system “has performed well,” the NHAS states that there are few tools to accurately detect people who are newly infected with HIV…[which] is critical because people who are newly infected with HIV are more infectious than those individuals who have been living with HIV for an extended period of time (NHAS 18)

Moreover, the NHAS emphasizes the importance of a comprehensive national HIV surveillance system, as “not all HIV surveillance sites track the same key measures in the same way (e.g., viral load, CD4)” (NHAS 18).

From this language, we can make several important deductions. First, that HIV/AIDS is being monitored on the national scale, and that this information directly influences policymakers’ and public health official’s targeting and evaluation of HIV prevention and care programs, as well as where future money will be directed toward to improve national efforts at HIV prevention and treatment. And second, we glean that not all HIV surveillance methods track the same health indicators (e.g., viral load, CD4 count, and so forth as is stated in the NHAS). Perhaps what is more important, however, is what we the NHAS does not clearly state or explain in its language regarding the National HIV Surveillance System. For example, we are left wondering who is “behind the desk” performing the surveillance (which, as it turns out, is
handled by the CDC’s Department of Health and Human Services (HHS)) (HIV Surveillance Reports). Moreover, while the NHAS implies that the National HIV Surveillance System does in fact track all key HIV measures, this is not clearly stated within the language. Furthermore, while the NHAS states that “there are few tools to accurately detect people who are newly infected with HIV”, we are unsure whether or not the National HIV Surveillance System is capable of providing us with such assurance, or if it is just a sort of “minor tool” to be used in the larger scheme of HIV prevention, treatment, and containment. These facts make us question what exactly what the National HIV Surveillance System is, then, and whether or not it should be considered a vital component of the more comprehensive HIV/AIDS framework that the NHAS pushes for.

Beyond this simple “objective” analysis, however, is an underlying analysis that deserves our attention. The type of analysis that I am referring to embodies the critical consideration of various factors regarding HIV reporting and surveillance, including, but not limited to: what forms of stigma or discrimination result from HIV reporting and surveillance; is the reporting name-based or anonymous, and what sociopolitical consequences does each form of reporting entail; and taking into consideration whether or not the terminology of a “national HIV surveillance system” is a legitimate form of fear-baiting, placing individuals “at-risk” for, or currently infected with HIV/AIDS in a state of anxiety (with the notion that the federal government is always watching over them, profiling their actions and behaviors and demarcating them along the various social binaries previously mentioned)? Beyond
the objective failures of the NHAS language regarding HIV surveillance, we must consider why federal HIV/AIDS policy employs the language of targeting populations through HIV surveillance, and whether or not such a policy results in the continued stigmatization and discrimination of PLWHA. Such an “underlying analysis” (as I call it) directly ties to the notions of stigma, discrimination, vulnerability of PLWHA, and a politics of disgust—all crucial components of the hidden HIV/AIDS agenda that this project is attempting to expose.

Much of my underlying analysis with respect to “HIV surveillance” language pulls from the work of Gregory Herek, John Capitanio and Keith Widaman in their article *Stigma, Social Risk and Health Policy: Public Attitudes Towards HIV Surveillance Policies and the Social Construction of Illness*. In their article, Herek et al expound upon the work of scholar Scott Burris, who introduced the term “social risk,” which he defines as the “danger that an individual will be socially or economically penalized should he or she become identified with an expensive, disfavored, or feared medical condition” (Herek et al 534). According to Burris, social risk “comprises both the objective threat of harm and the subjective perception of risk for harm” (Herek et al 534). As can be deduced from their article’s title, Herek et al, in their work, attempt to expound upon the work begun by Burris, extracting out any potential connection between stigma, social risk, and current HIV surveillance policies.

In their study, Herek et al discern the attitudes of respondents towards various HIV surveillance strategies, particularly name-based reporting and anonymous
reporting. The results of their study reveal that public attitudes toward HIV surveillance “were significantly affected by whether seropositive individuals’ names would be reported or not” (Herek et al 536). Consequently, only “one fourth of respondents who were asked about name-based reporting supported it…[while] those who were asked about anonymous reporting supported it by margins of roughly 2-to-1” (Herek et al 536). Importantly, Herek et al contribute the respective difference in public attitudes to individual concerns about being stigmatized if they tested positive for HIV in the future (Herek et al 536). In further explanation, Herek et al suggest that “widespread opposition to name-based reporting reflected concerns about privacy and stigma rather than opposition to reporting per se” (Herek et al 536).

Importantly, Herek et al’s work significantly informs our understanding of HIV surveillance strategies, as well as our analysis of language regarding the “National HIV Surveillance System.” Primarily, the findings from Herek et al’s study reveals that through the lens of social risk, public attitudes regarding various HIV surveillance policies do in fact reflect individual perceptions of the perceived stigma and discrimination resulting from name-based versus anonymous HIV reporting. The perceived risk of being additionally stigmatized and discriminated against for testing positive for HIV – as well as the consequent forms of surveillance that follow being officially recognized as seropositive – act as significant disincentives toward HIV testing. Additionally, Herek et al critically call attention to the fact that “[d]ebates about health policies such as HIV surveillance procedures…should be understood in the context of the ongoing social construction of AIDS as an illness” (Herek et al 534).
That is, if a policy such as name-based reporting “become widely perceived as an instrument of stigma, its adoption may increase the social risk experienced by people with HIV despite the best efforts of public officials to reduced the likelihood of enacted stigma” (Herek et al 534). Paralleling aforementioned discussions about both the composition of stakeholders in a social issue as well as the make-up of target populations, Herek et al’s work reemphasizes the contextual nature of social problems, as notions such as forms of stigma, discrimination, perceived vulnerability, and social risk are all subject to fluctuate and differentially affect various segments of the population based on the history of the social issue, its current sociopolitical status, and its influence on public policy and the social realities of stakeholders.

In addition to the affects of social risk, stigma and discrimination on public attitudes toward HIV surveillance strategies, I ask whether or not NHAS language regarding the “National HIV Surveillance System” ought to be considered a legitimate form of “fear-baiting.” This term, which I use rather loosely herein, derives from my perception of the historical nature of the hidden HIV/AIDS policy agenda, which I argue has been a utilized as a guise for sociopolitical control and power contestation, carrying out the government’s objective of maintaining or improving status quo power relations behind “closed doors” and the reach of public actors and citizens. Specifically, I use the term “fear-baiting” to mean a mechanism of achieving political objectives through public policy that frightens or makes anxious those groups or communities that policymakers are attempting to control. Through the effective use of fear, I argue that individuals are more likely to be in a heightened state of social
anxiety, less likely to act in ways that accompany perceived social risk, and, consequently, are more apt to do as policymakers wish.

With this in mind, I ask: does the terminology of a “National HIV Surveillance System” elicit fear and anxiety on the part of PLWHA and those portrayed as “at-risk” for infection? To my knowledge, such a question has yet to be asked by HIV/AIDS-related stigma scholars, and, thus, such a question lends itself purely to informal conjecture (as I myself have not had the opportunity to pursue such research at this point in time). However, I believe that such a question needs to be asked when it comes to language such as a “National HIV Surveillance System,” which creates an bifurcated system in which it is the government in one corner, and the individual in the other. Such schemas represent the notion of the individual versus the government, a sort of adversarial system in which the government is not “of the people, for the people, by the people,” but, rather, an institution with its own separate objectives and conscious, fighting with citizens for the control of power. Such a notion is blatantly inconsistent with the essence of American democracy. And, if we are compelled to believe that the answer to this question lays in the affirmative, then we must also be convinced that such terminology serves as a direct impediment towards espoused national objectives and visions of progress.

Returning back to the notion of social risk and public attitudes toward HIV surveillance strategies, Herek et al conclude their analysis with proposed solutions to the status quo policies of HIV surveillance. Concisely, Herek et al assert that more
effective surveillance policies “should not only include stringent confidentiality safeguards but also make the public aware of these safeguards and of public professionals’ ongoing commitment to eradicating AIDS stigma and discrimination” (Herek et al 539). Furthermore, Herek et al posit that such a commitment “could be demonstrated by initiation of explicit antistigma campaigns related to HIV at the national, state, and local levels” (Herek et al 539). Importantly, Herek et al’s notion of more effective surveillance strategies and policy fall right in line with my notion of more inclusive, egalitarian, compassionate health care policy. Not only does it clearly state the need for confidential, anonymous reporting – something that would greatly reduce the perceived social risk of, and potential stigma and discrimination resulting from, HIV testing and surveillance – but it also highlights the importance of public awareness of such facts, and the need for an explicit commitment by public health officials and policymakers to eliminate HIV/AIDS-related stigma and discrimination.

While the NHAS does make a clear commitment to ending HIV/AIDS-related stigma and discrimination, any such discussion of stigma and discrimination resulting from HIV surveillance strategies is wholly nonexistent. Moreover, the NHAS fails to both clarify which reporting policy – name-based or anonymous – the National HIV Surveillance System utilizes (which in fact is anonymous, and can be found on the CDC’s HIV Surveillance Reports webpage), as well as convince us that the general public is aware of this policy. The only reference made to reporting policy is that the NHAS emphasizes the need to protect people who are openly living with HIV (NHAS 36). However, this is tremendously unclear, and follows a statement encouraging the
disclosure of HIV status by seropositive individuals—a remark that seems a bit insensitive, considering the federal government’s recognition of the “shame and embarrassment” the accompany testing positive for HIV (NHAS 36). Similar to the prior two sections on target populations and behavioral interventions, NHAS language regarding HIV surveillance strategies is not problematic in and of itself per se; but, rather, becomes problematic through the way in which it is used or not used. In full agreement with Herek et al’s notion of more effective HIV surveillance policies, I argue that federal HIV/AIDS policy language needs to be modified and clarified in order to produce the type of more inclusive, egalitarian, and compassionate health care system we seek.

**Conclusion**

In sum, this chapter has looked at three subsections of language use – that of target populations, behavioral interventions, and HIV surveillance strategies – in an effort to deconstruct HIV/AIDS health policy language and strive towards a type of more inclusive, egalitarian, compassionate legislative language that better reflects our public health objectives and vision. Analysis of each of these sections revealed that how the language was employed was much more problematic than the content of the language itself. In the case of target populations, we see that policies targeting particular individuals and communities for HIV prevention and treatment efforts allude to a sort of “special treatment” and separate status from the “general population.” Such language detracts from the notion that all Americans deserve equal
treatment and access to robust, high-quality health care services. In the case of behavioral interventions, we find that language referencing “risk behaviors” taken up by PLWHA and those perceived to be “at-risk” for infection could be taken as an attack on the character and nature of such individuals, and demarcates them the rest of “normal” society. Finally, in the case of HIV surveillance strategies, we glean that lack of clarity regarding reporting policy, what HIV indicators the National HIV Surveillance System specifically measures, who is in charge of and accountable for doing the surveillance work, as well as the potential link between the terminology of “State surveillance” and the notion of fear-baiting make for bad policy that seems to contradict the recognition of the type of shame, stigma, and embarrassment that accompany HIV-positive disclosure.

Again, the above analysis is by no means intended to be an individual attack against the policymakers and public health officials who devised the NHAS. Rather, it is meant to be a heartfelt attempt at deconstructing federal HIV/AIDS policy language in the effort to strive towards more inclusive, egalitarian, compassionate health care legislation that can help us achieve our national health objectives of reducing HIV/AIDS-related disparities, infection and transmission rates, and increasing the quality and retention rate of HIV/AIDS treatment programs. The NHAS does much to move us in this direction, making an explicit commitment towards a more comprehensive prevention and treatment framework that recognizes the failures of prior HIV/AIDS legislation, and which takes into account the fact that “there is no single ‘magic bullet’ that will stem the tide of new HIV infections” (NHAS 15). The
effective dissemination of HIV educational, prevention and treatment information, as well as the need to have data regarding how many individuals are currently infected with – and affected by – HIV/AIDS are all critical components to this type of comprehensive framework. However, I argue that federal HIV/AIDS policy can do a better job in constructing language that is more inclusive, egalitarian, and compassionate towards PLWHA and the greater HIV/AIDS community, and that more accurately reflects the social realities that these individuals and communities face.
Chapter 3: Reconstructing Mutual Respect from the Margins

In this final chapter, I hope to transition from the examples of disrespectful and discriminatory language found throughout the NHAS towards developing my own notion of more inclusive, egalitarian and compassionate healthcare policy. Such a notion hinges upon the reconstruction of respect (both how we envision it, and how we practice it in a deliberative, communicative democracy such as the U.S.) from “the margins,” meaning an attempt to understand and develop a notion of respect which takes account of – and strives to more adequately include – the interests, needs, and social realities of marginalized groups in the process of policy formation and decision-making. My notion of mutual respect, both as a posture and practice to foster a more inclusive and egalitarian deliberative democracy, is founded upon several central tenants, including: a communicative model of democratic inclusion, an asymmetrical notion of vulnerability and respect, and the concept of mutual respect as a political tool, rather than a moral guide in democratic practices. And, while by no means hoping or implying that this reconstructed notion of mutual respect will or can be a panacea for ending the “HIV/AIDS epidemic,” I do believe that it can both aid in revisualizing how we perceive inclusion and diversity in our society, and, consequently, lead to a more equitable and accessible healthcare system capable of serving the needs of all Americans.
Inclusion and Democracy

The strain of democratic theory that has most dramatically influenced this project’s perception of mutual respect within a deliberative context flows from scholar Iris Marion Young. In her work *Inclusion and Democracy*, Young begins with the basic notion of what democracy is and what democracy is about, eventually progressing to demonstrate what inclusive democracies look like, why we ought to strive for them, and what key mechanisms must be in place to keep the system a well-oiled machine, with equal opportunity for all to participate. Importantly, Young’s notion of the most effective form of democratic participation is well designed to fit into the current HIV/AIDS debate. Not only does it offer ways of getting past the increasingly diverse population that we have, but it also strongly promotes the inclusion of all Americans in deliberative and decision-making processes, especially the inclusion of those who are most affected by the issue at hand. This notion of inclusion and/in democracy does a lot for the HIV/AIDS debate because it highlights the importance of mutual respect as a political concept, rather than a moral one, paving the way for us to reconceive how we do politics and interact with others in decision-making practices and processes.

Herein, Young defines democracy as

not only a means through which citizens can promote their interests and hold the power of rules in check…[but also] a means of collective problem-solving which depends for its legitimacy and wisdom on the expression and criticism of the diverse opinions of all the members of society (Young 1:6)

On this account, democracy is a form of government that attempts to protect and serve its citizens’ interests and needs through problem solving endeavors. Centering itself on
the fact that problems arise in human societies, and that government is in place to help resolve these issues, we can see the connection here between Young and Stone, who was previously mentioned as saying that the essence of democracy is the struggle over ideas. Overlapping these two notions, we can see how the existence of social problems and the diversity of ideas and beliefs – both inherent to human life – coalesce, evolving into the messy realm of politics as we know it. And, often, the issue with politics becomes how to learn to work with one another through our differences, rather than actually solving the social issue itself.

Developing her basic notion of democracy, Young further asserts that the most effective form of problem solving is achieved through “inclusive democratic practice…[which] is likely to promote the most just results because people aim to persuade one another of the justice and wisdom of their claims” (Young 1:6). According to Young, inclusive democratic practice not only entails formal inclusion of all willing and able citizens in the deliberative and decision-making processes which lead to policy formation and legislation, but also the fact that individuals “are open to having their own opinions and understandings of their interests change in the process”, as they are convinced of more compelling ways to achieve equality and progress (Young 1:6).

From here, Young moves on to the more specific notion of a communicative model of democratic inclusion, which “theorizes differentiated social segments struggling and engaging with one another across their differences rather than putting these differences aside to involve a common good” (Young 1:18). Central to this
notion of democratic inclusion is the interaction of citizens in dialogue that takes account of their diverse experiences, interests and social frameworks. As Young states, a communicative model of democratic inclusion ought to be conceived of as an environment in which citizens work across their differences rather than putting them aside to solve social issues. Fundamental to Young’s argument are two critical deductions. First, that we are inherently different due to our individual and diverse experiences, and that no one individual may experience or perceive things in the same way that we do. And, second, that we ought not try to divest ourselves of this diversity. Our individuality is an inherent aspect of human existence. No matter how hard we try, we may never be able to achieve a society in which we are all act and think similarly, and this is an undesirable and impossible aspiration.

These ruling tenants provide the basis moving forward for Young, as she further bounds her notion of inclusive democratic deliberation. For Young, not only does inclusive democratic practice require individuals working across their differences and to be willing to change their own opinions and understandings as they engage with and are persuaded by others’ arguments, but also that there are basic conditions of “equal opportunity to speak and freedom from domination…[which] encourage all to express their needs and interests” fully and without fear of being discriminated against or excluded for doing so (Young 1:30). Such equal opportunity and freedom for Young is derived from an underlying notion of “being reasonable”, which is intimately linked to basic notions of respect. According to Young,

one cannot express disagreement with, or criticism and judgment of, the actions and opinions of others in terms that imply that one’s opponents are less than human or that their views do not deserve an equal hearing because of who they are (Young 1:48)
Such criticism and judgment lends itself precisely to the type of discrimination and tendencies towards exclusion that cripple inclusion and the acceptance of diversity in democratic deliberative practices. Such criticism and judgment falls into what Young, among others, call the “essentialist approach,” similar to Stone’s aforementioned notion of the “rationality project.” As soon as we begin to view and treat one another as unequal co-deliberators, or as adversaries in the decision-making process (battling to see who’s argument comes out on top), we lose respect for one another as equal fellow citizens, and co-contributors to this nation. Falling prone to the logic that there must only be one way to solve a particular problem, that all other suggestions are inherently “incorrect,” and that those who disagree with the “proper approach” ought to have their voices excluded from the/further decision-making processes denies individuals and co-deliberators their due esteem and their status as equally impacted citizens by governmental policy and practices. It silences and denies the fluidity of social identity and individual diversity, and makes impossible future inclusive democratic practices.

Importantly, what this project has done thus far has been to reveal how the HIV/AIDS debate has historically been, and continues to be, a situation in which not all actors receive equal voice and opportunity to participate in the decision-making process. As the Global Network of People living with HIV (GNP) asserts,

[where people living with HIV are involved, their participation is still often tokenistic and usually in project implementation rather than in the designing of policies or programmes. There is little involvement of women and young people living with HIV in policy-making decisions that affect their lives. Even within the Country Coordinating Mechanisms (CCMs) of]
Due to a variety of factors that disincentivize or prohibit individuals and communities from participating in deliberative and decision-making processes (HIV/AIDS-related stigma and discrimination, lack of housing or transportation, lack of knowledge of how to get involved in these processes, etc.), PLWHA have been actively removed from or silenced in institutions and processes of policy. With regard to the HIV/AIDS epidemic, we can safely conclude that, even though large gaps have been closed in the way of formal inclusion into the process of PLWHA, we have yet to achieve the type of fully inclusive democratic practice that Young advocates. Even when advocacy organizations representing the interests and needs of PLWHA have found their way into these confined settings, what we still see is the formation of federal public health policy such as the NHAS largely written by a small subset of elites such as ONAP who have themselves remained largely distant from the social experiences and realities of PLWHA and the HIV/AIDS community writ large (NHAS 3).

**Asymmetrical Vulnerability and Reciprocity**

With the failure of the historical HIV/AIDS decision-making process to achieve the type of inclusive democratic practice that we seek, we must move towards indentifying the specific factors or influences that prohibit us from actualizing our goals. Informing this task is scholar Amber Knight’s manuscript draft *Disability as Vulnerability: Redistributing Precariousness in Democratic Ways*. In her article, Knight centers her discussion on two issues, disability and vulnerability, critiquing
“competing conceptions of vulnerability and its relation to politics, focusing on the writings of Alasdair MacIntyre, Michael Sandel, and Judith Butler”, examining “how political appeals to a shared human vulnerability could potentially deconstruct the able/disabled binary that continues to exist in the case of disability” (Knight abstract). Posing HIV/AIDS as the “disabling” disease in this case, I assert that Knight’s critique of conceptions of vulnerability and its relation to politics does much in the way of informing the current HIV/AIDS debate and decision-making processes, moving us closer yet to the type of inclusive democratic practice that Young calls for.

Remarking upon the socially constructed binaries of able/disabled people, Knight begins her discussion noting that “Americans regard able-bodied and disabled people as effectively two-separate species, whereas Swedes regard them as humans in different life stages” (Knight 1). Similar to my previous discussion of the various socially constructed binaries embedded in the historical and current HIV/AIDS debate, Knight’s claim reveals how these binaries have tangible and lasting effects on how we interact with and perceive fellow citizens. Knights comparative note between the perception of Americans and Swedes regarding those constructed as “able-bodied” versus “disabled” exposes how the process of constructing these identity boundaries imparts value judgments on the ways in which we think of and, consequently, treat, various individuals and communities, particularly PLWHA. Instead of viewing HIV/AIDS+ individuals as humans who are at a different point in their lives then those of us who are seronegative (as Swedes do), Knight claims that Americans are fundamentally socialized into believing that PLWHA (among other “disabled”
identities) are viewed as being intrinsically different from us. This binary is infused with the myriad discriminatory stereotypes of HIV/AIDS, mainly, that these individuals are hypersexual and “dirty,” that they are engaging in “risky behaviors” that have led to their current diseased status, and, accordingly, that they are individually responsible for their undesirable condition.

Unfortunately, as we have seen, this logic of identity has led us to our current failing healthcare and policymaking systems, which continue to inadequately provide the type of robust, high-quality HIV/AIDS treatment and prevention services that all Americans deserve, and which continue to formally and informally exclude PLWHA and the greater HIV/AIDS community from involvement in the decision-making process. Fundamentally viewing PLWHA as intrinsically separate and distinct from our (non-seropositive) selves, we maintain democratic processes which pose these individuals not as co-deliberators, but, rather, as the subjects of our deliberation, and whose lives we must regulate through our policy decisions.

According to Knight, this framework has everything to do with how we as a nation perceive disability, disease, diversity and vulnerability. For Knight, the solution to our continued failure to progress in this dimension lies in the deconstruction of this binary perception altogether, and a revised political appeal to vulnerability. Knight asserts that if

we accept the principle that we are all vulnerable to varying degrees at different points along the lifecycle, disability is understood as a dimension of human diversity rather than a tragedy, deficit, or abnormality (Knight 2)
This fundamental shift in how we view individuals living with a life-threatening illness such as HIV/AIDS – as being at a different point of their lives than us, rather than being a intrinsically different than us as human beings – is a radical shift from how we currently think of “the sick.” While it is true that many of us will never contract HIV/AIDS, and many of us may never even be personally affected by someone we know who has HIV/AIDS, as the NHAS states, already 50% of Americans are either currently living with HIV/AIDS or know someone who is, and this number continues to grow each year. Moreover, simply because we ourselves may never contract HIV/AIDS, or may never have a family member or close friend who becomes seropositive, does not mean that we ought to treat PLWHA and the HIV/AIDS as distinctly different humans than ourselves. As was made evident above, human life is made unique precisely because of our individual and diverse experiences, and this can be a valuable asset in a socially conscious society, as long as we are sure to work across these differences and recognize individual experiences, rather than try and ignore them or “put them aside” in order to solve our societal problems. Changing how we view individuals and communities “disabled” by diseases such as HIV/AIDS is one important way to accomplish this challenge, and to continue moving towards achieving our national health objectives.

Elaborating upon the specific benefits derived from such a paradigm shift, Knight asserts that “a political appeal to a shared human vulnerability can deconstruct the able/disabled binary that continues to prevent political progress on the issue of disability” (Knight 3). That is, because “nobody can foresee when they will experience
illness or impairments,” we all ought to consider ourselves “vulnerable” to some extent, and that “our political systems should be designed to accommodate the possibility” (Knight 1). In direct relation to HIV/AIDS and access to healthcare services and such as treatment and prevention, this would mean that our healthcare system would be prepared to provide for the needs of all individuals who are at different points in their lifecycles—whether this means that they are “healthy,” mentally/physically ill, have contracted a life-threatening disease, etc., and that individuals, regardless of their health status would be treated with equity and without discrimination solely based on their social identity.

Such a shift in our social framework would do much in the way of removing the stigma PLWHA and the HIV/AIDS community currently suffer through the belief that they are in need of “special” protections or assistance (i.e., the type of belief that is harbored and maintained by the language such as that of “target populations”).

Knight remarks that

[according to MacIntyre, we are equal to the extent that we are equally vulnerable to the unpredictable fate of mortal animals. Nobody can escape the risk of impairment, disease, aging, and dying. In addition, the equality found in our common vulnerability introduces strong commitments for collective political change (Knight 4)]

The notion that humans share vulnerability (in this sense) to exposure and risk to a variety of environmental and social factors serves as a political basis for moving beyond such discriminatory “special treatment” beliefs. In line with the notion that differently “disabled” people are simply at different points in their lifecycle, the notion that we are commonly vulnerable (by virtue of being human) allows us to expect and respect the fact that some of us will unfortunately suffer such harms. More
importantly, it allows us to understand the fact that, no matter how badly we want to believe it, life is not a zero-sum game. As Knight makes clear, “some people at times will need more resources than others [due to their health conditions] and that others are obligated to provide more when they are able to [due to the understanding of our shared vulnerability]. It follows that reciprocity is often asymmetrical” (Knight 5-6).

Importantly, while this revised political appeal to vulnerability does much for the current HIV/AIDS epidemic and debate, we would be remiss if we did not also acknowledge the ways in which vulnerability is not experienced or distributed equally in our society. Knight, in further explanation, states that a “[w]hile human vulnerability is a shared condition, it is not shared equally in a context of political inequality” (Knight 7). Acknowledging the fact that social hierarchies exist in our nation and that such hierarchies hold tangible consequences on the political and social realities individuals experience (in relation not only to “social risk” for HIV/AIDS, but also crime, poverty, access to stable housing and employment, access to political mechanisms of influence, and so forth), Knight contends that our world is one that is “structured to respond to some people’s vulnerabilities better than others, so [that] risk and exposure is [sic] manifested in uneven ways” (Knight 7). These structural inequalities are not in fact random, but, rather, have been created and sustained through the construction of such aforementioned social binaries, their concomitant morally charged judgments on the character and identity of individuals, and structures of power such as racism, sexism, classism, ableism and imperialism which lead to an
unequal distribution of social, political and economic resources to various segments of the population (Knight 14).

Thus, critical to this revised political appeal is Butler’s distinction between “the universal condition of vulnerability from its particular experience” (Knight 13). As Butler reveals, while “human lives are universally vulnerable, precariousness is not distributed equally and is therefore experienced in a particular way” (Knight 13). By taking power relations into account in the differential experience and distribution of vulnerability, Knight acknowledges that “we are all alike only in having this condition separately, and so having a common condition that cannot be thought of without difference” (Knight 16). Again making the connection to Young’s notion of working through our inherent individuals differences, rather than around them, Knight’s appeal to vulnerability as a basis for political solidarity and as a tool for deconstructing the able/disabled binary makes explicit recognition of the fact that we cannot remove ourselves of our individual differences, even in the case of a shared human vulnerability. Such a “difference-conscious” approach (if you will) positively and significantly contributes to the progress of the HIV/AIDS debate and “ending the epidemic,” as we take notice of the differential distribution of resources in society with a compassionate response, compelling us to effect political change to level out the playing field for those who (PLWHA, in this case) are at a different stage in the lifecycle.

More importantly, the shared basis of vulnerability takes us beyond the limitations experienced by something such as a social identity, which often serves as a
limited and poor basis for political solidarity. As Knight explains, “since subject formation is an ongoing and unstable enterprise and precarity [the universal condition of human vulnerability] cuts across ID categories”, such a basis for coalition building and solidarity is limited by its very nature. Individuals are not only subject to change their identity performance and self-perception, but social identities themselves evolve with society, as new understandings of identities make way, as new identities emerge, and as the socio-political context transforms with developments both domestically and abroad. Thus, a better basis for political solidarity is a political appeal to our shared vulnerability, one that both recognizes the precarity (universal condition) and precariousness (individual experience) of vulnerability, and which takes into account the ways in which society itself is structured to produce inequalities.

**Mutual Respect as a Political Concept, Not a Moral One**

In developing my own notion of mutual respect as a spearhead for progress in the HIV/AIDS debate (and, more broadly, for democratic deliberative practices writ large), the last crucial distinction to be meted out is the nature of my concept of respect. Whereas many philosophers and individuals both past and present have presented respect as a moral concept, a notion that is defined by abstract theories and understandings of various political “states of nature,” the notion of mutual respect which I promote here is necessarily distinct in that I view it is a political tool, not a moral guide or compass. I argue that mutual respect in the case of the HIV/AIDS debate – as well as various other social crises and dilemmas – can serve as both a
political tool and practice in deliberative settings, providing us with a grounded and concrete foundation for how we can better interact with and perceive individuals in the name of making sociopolitical progress. It is a tool and practice defined and driven by the notions of asymmetrical reciprocity, our shared (yet differentially distributed) human condition of vulnerability, and “difference-consciousness” described above, which are central tenets for any polity seeking more diverse and inclusive practices. It is a tool and practice that hinges upon the recognition and extension of respect to other individuals as co-contributors to the successes and failures of this nation, rather than a respect for the law as a moral guide for present and future state actions.

In further explanation of the distinction between the political nature of my notion of mutual respect versus the typical moral conception of respect promulgated by others, I turn to Bonnie Honig’s critique of Kantian notions of respect in her work *Political Theory and the Displacement of Politics*. Herein, Honig describes and critiques Immanuel Kant’s development of the notion of respect as a moral concept that does not go far enough or achieve the type of inclusive, egalitarian political practices we seek as a nation. As Honig asserts,

> a close reading of Kant’s theorization and justification of respect shows that, for the most part, Kant’s respect is for the moral law, not the person. At times, Kantian respect is for the morally worthy parts of persons, but never for persons tout court; and it’s consistently never for those who are *other*, only for the possibility of their conversion to moral worthiness [emphasis in original] (Honig 18)

From Honig’s comment here we glean that from Kant’s perspective respect hinges upon the recognition and acceptance of the law as a moral guide and order. According to Kant, some aspects of respect deal with the characteristics of individuals as human beings, and extends recognition to the “morally worthy parts of persons” consistent
with the law; however, as a concept it has less to do with the rights and liberties of individuals, and more to do with their behavior in accordance with the law.

Elaborating on this point, Honig argues that Kantian notions of respect – which are widely revered for “elevating and enshrining man as an end unto himself” – turn out to “consist also in the requirement that he order his behavior and his thoughts in conformity with certain moral ends” (Honig 18). From Kant’s perspective, what we conclude is that respect is extended to those who conform under the law, rather than a practice of the law that safeguards the rights and integrity of individuals in accordance with the state’s governmental function.

Critically, Honig’s critique of Kant above allows us to see how such notions of respect necessarily become problematic when what is viewed as “morally agreeable” by most (AKA the national law) results in the denial of respect and the protection of certain inalienable rights of some. In the case of the current HIV/AIDS debate, we can extend this perspective to the view of PLWHA as “threatening,” “sick,” non-contributing members of society—a notion that denies them their due respect, rights and integrity as individuals because of their undesirable and resented physical status. For many Americans, the contraction of HIV/AIDS is linked to deviance from the moral law (which has been infused with and maintained by hegemonic, heterosexual notions of how individuals ought to behave and think in society through generations). Consequently, viewing PLWHA as socially and legally aberrant persons who are deserving of their health status provides justification for their continual disrespect,
lack of access to quality and robust healthcare services and treatment that they need, and the formal and informal modes of exclusion they face in deliberative practices.

Unfortunately, such notions of respect – that individuals whose actions and behaviors deviate from the law’s precepts find themselves outside the possibility of respect – are directly opposed to the precise form of respect necessary for “ending the epidemic” and creating a more inclusive, egalitarian, compassionate healthcare politics. Such Kantian notions of respect inform the foundations of disrespect and exclusion that comprise our currently insufficient, inegalitarian healthcare system. As Honig points out, for Kant “the state and its enforcement of positive law do not merely structure and weight incentives; they provide the necessary conditions for the development of individual autonomy and moral personality” (Honig 19). And, consequently, when a nation such as the U.S. is founded upon a fundamentally hierarchical, exploitative structure that serves to extend benefits and rights to the elite, conforming few at the expense of others, what we are left with are notions of “individual autonomy and moral personality” that are out of sync with and impossible for the various forms of individual expression within our increasingly diverse social environment.

For Kant, the “progress of the species” is the ultimate justification for his “political orderings as well as the solace for those whose experience of the moral and political order is less than fulfilling and perhaps even violent” (Honig 19). That is, citizens ought to respect the law as a moral arbiter on principle, and those who are dissatisfied with or experience misfortune under the law should essentially suffer in
silence, accepting that the disadvantages they face are “for the greater good.”
Unfortunately, such a notion provides little to no help in our efforts to achieve a more
egalitarian and compassionate healthcare system and politics. Granted, it is foolish and
unreasonable to believe that all citizens ought to lead completely happy and fulfilling
lives under the law, and that no individual will ever suffer harm or misfortune due to
certain provisions of the law. Developed and employed by human beings, the law
ought to be expected to imperfect and to err at times. This is precisely why we accept
the fact that the law evolves over time to meet the demands and protect the interests of
individuals in a constantly developing and changing society. However, in the case of
HIV/AIDS, what we have is not simple human error or legal imperfection; rather,
what we see are laws and institutions in place that deliberately and significantly affect
the lives of PLWHA in devastating ways, solely on the basis of their social identities.
More importantly, what we have is a class of individuals who are socially and legally
prohibited a series of rights (primarily, access to equal and comprehensive healthcare
services, as well as participation in deliberative settings as co-participants in the
process of policy formation and change) due to them on the basis of their equal
citizenship status as Americans.

In a broader stroke, what we can conclude is that the American superstructure
– founded upon hierarchy and mechanisms of power that protect the benefits of a
select few to the detriment of others – make Kantian notions of respect problematic in
relation to broader notions of progress, and specifically to notions of progress in the
HIV/AIDS debate. Kant’s notion of the law as a moral guide that will seemingly
always lead toward progress did not take into account the possibility that sometimes
the law cannot get us to where we want to go. Sometimes we have to work outside of
or around the law to achieve what we seek as a nation. Consequently, this means that
sometimes the only viable route for progress is found in political and social
movements, institutions, and/or organizations that strive for social change.

In the case of the HIV/AIDS epidemic, this is where my notion of mutual
respect – as both a tool and practice for fostering a more inclusive, egalitarian,
compassionate healthcare politics and system – fits in. Instead of relying on status quo
law to change to more adequately serve the needs and interests of PLWHA, I argue
that perhaps there is something wrong with the decision-making process itself, that
perhaps the law will never get to us to where we need to be if we do not reconsider
how we create the law itself, if we do not rethink how and who enters into decision-
making arena to create or modify legislation. My notion of mutual respect, as a
political tool and practice that redefines how we enter into deliberative settings, how
we interact with and perceive our co-participants in the process, is a part of this
process. In the case of the American HIV/AIDS debate, if what we seek is a more
inclusive, egalitarian, compassionate healthcare politics, a politics that can ensure that
all individuals (including PLWHA) have access to the types of healthcare services and
treatment that they deserve as equal citizens in this nation, then we have to strive for a
social transmogrification of sorts. We have to seek social change that transforms how
“the general population” perceives PLWHA (as well as other “disabled” and socially
marginalized individuals) from the view of undeserving, resentful, and peripheral
individuals to one of equally deserving, co-contributing and co-affected individuals of this nation that are due our respect as fellow human beings. We have to seek social change that takes into account our shared (yet differentially distributed) human vulnerability, notions of asymmetrical reciprocity, and notions of diversity and inclusion that can better serve our efforts towards progress. And, most importantly, we have to seek social change that recognizes the ways in which our society is already structured to differentially and unequally distribute benefits and privileges to some to the detriment of others in order to make our way forward towards more inclusive and egalitarian deliberative practices and practices of democracy.

Concluding her critique of Kantian notions of respect, Honig expounds upon this notion of progress, asserting that “in lessening the violence and adversity of the state of nature the juridical state exercises a violence of its own, a violence that is the product of the state’s organization and concentration of power” (Honig 37). That is, that government, by nature, tends towards its own hierarchies and discriminatory practices that obstruct progress towards more egalitarian and inclusive democratic practices and policies. Acknowledging this fact, we realize that if we want stable, long-lasting change, it will necessarily mean changing the nature of government itself, of changing the norms and value judgments infused in the law and all of the nation’s citizens that have developed and sustained the discriminatory and exclusionary practices of the past and present. While this may seem to be a daunting and impossible task, it is something that must and can be done. Looking back to past examples of major social change – the women’s suffrage movement, the civil rights movement,
landmarks legal rulings in cases such as *Loving v. Virginia* and *Lawrence v. Texas* – we see how transformative social movements have removed the criminal status from the identities and behaviors of previously resented and marginalized individuals, effectively transitioning them from the outskirts of the “deviant” and “resented” realm to being considered fellow and equal citizens. Moreover, past examples such as these give us hope that fundamental shifts in the way individuals interact with and think about one another are viable and achievable options towards progress. They give us hope that even though this transformative process may take years or even decades to achieve, and that even though it may take the efforts of many individuals, a more inclusive, egalitarian, and compassionate healthcare politics and system is at the end of the tunnel. They give us hope that one day we may be able to perceive, treat, and extend respect to PLWHA as equal citizens and co-contributors to this nation’s successes and failures, and as individuals who have an equal stake in this nation’s future.

**Towards More Respectful Practices of Engagement**

In the effort of laying out my arguments for what is necessary for a transition towards more respectful, compassionate practices of democratic engagement and healthcare politics, it would be useful to provide some practical examples of what I believe we ought to be striving towards. While none of the following examples may be exactly what we are looking for as far as “perfect practices of mutual respect” may go, as mentioned previously, such a notion is improbable in and of itself, and is not what I
believe we should be striving towards. Rather, one thing that this project has
definitively shown us is that democracy and politics are never clear-cut institutions
with simple problems that have simple solutions. They instead are necessarily messy
creatures by their increasingly diverse, contextual, and evolving natures. As such, we
have to do the best with what we have got, and this often means striving towards a
“more perfect practice”—in this case, striving towards a more inclusive, egalitarian,
and compassionate health care politics and system (rather than a necessarily ‘perfect’
one that meets and accomplishes everything we need right now).

Accordingly, this final section is dedicated to providing some current practices
of democratic engagement and healthcare politics that more adequately achieve the
future we seek. Some of the policy recommendations, principles and core values are
derived from the international context—from international HIV/AIDS organizations
such UNAIDS and resources such as the Greater Involvement of People living with
AIDS (GIPA) Principle—rather than stemming from domestic movements and
advocacy organizations. Granted this, however, two important points are to be made.
First, that in the effort to seek best practices and policy recommendations for our own
HIV/AIDS healthcare practices and system, it can prove useful to look abroad for
examples of how other institutions, governments and organizations are doing
healthcare, as a means of comparing and re-evaluating our own status and politics.
And second, that the HIV/AIDS epidemic is not only a U.S. health and policy issue,
but also an epidemic that reaches and affects all countries worldwide. While varying
demographic, social, economic, and regional differences necessarily affect the
implementation of various prevention and treatment services in respective countries, the confluence of contributing factors to the epidemic, as well as sociopolitical consequences experienced by HIV/AIDS international communities, have more similarities than differences across the globe. As such, it is in our best interest to look to international best practices and guidelines for healthcare practices and policies that exemplify the types of more respectful practices of engagement and language that we strive for as a nation.

The majority of policy recommendations, principles and core values that this section pulls from come from the Global Network of People living with HIV (GNP+)—an international HIV/AIDS advocacy network that seeks to improve the quality of life of PLWHA. In January 2011, GNP+ developed “Positive Health, Dignity and Prevention”, a policy framework laying out HIV/AIDS recommendations to international governments (GNP+). According to the policy framework, Positive Health, Dignity and Prevention is not just a new name for the concept of HIV prevention for and by people living with HIV, formerly known as ‘positive prevention’. Rather, Positive Health, Dignity and Prevention is built on a broader basis that includes improving and maintaining the dignity of the individual with HIV, to support and enhance that individual’s physical, mental, emotional and sexual health, and which, in turn, among other benefits, creates an enabling environment that will reduce the likelihood of new HIV infections (GNP+ 6)

Explaining the core value and mission inspiring these recommendations, this statement does much in the way of shifting the current focus of HIV/AIDS healthcare politics and policies from infection/data-focused to individual-focused—highlighting the needs and desires of the individual living with HIV/AIDS, as opposed to the national interest in driving down infection/mortality rates. While these two viewpoints are not mutually exclusive (rather, arguably they go hand-in-hand), we must recognize the
importance of this shift in focus. Importantly, an individual- or subject-focused lens prompts us to more adequately and comprehensively recognize and take into account the needs and interests of PLWHA, as these factors are what fuel and drive current and future healthcare practices and policies. Rather than primarily focusing on epidemic statistics and the epidemiological profiles of differentially impacted communities (as our current practices and policies compel us to do) which reveal the status and progress of HIV/AIDS but critically ignore the sociopolitical and economic factors which contribute to this process, the subject-focused account allows us to lay the groundwork for healthcare legislation that centers around the needs, interests and rights of those most directly affected by the disease itself. With this as the starting point, consequently, we can thus create and tailor effective, context-specific policy recommendations and practices that better serve both PLWHA and our national healthcare objectives moving forward.

From here, GNP+ moves forward with policy recommendations that center around increasing the capacity of organizations and networks of PLWHA at global, regional, and country levels to “participate as full, equal, and essential partners in the planning, implementation, monitoring, and evaluation” of HIV/AIDS healthcare legislation (GNP+ 7). These recommendations stem from, and attempt to combat, various myths or misunderstandings about HIV/AIDS in general. These misunderstandings include the fact that many current HIV prevention approaches treat PLWHA as “potential vectors of new infections, rather than individuals with complex and competing needs and interests” (GNP+ 9). In line with the criticisms laid out in
previous sections of this chapter, such a perspective fails to recognize PLWHA as fellow, equal citizens capable of being educators and effective change agents, and makes impossible the extension of respect to said individuals as such. Portraying PLWHA as simply “vectors of infection”, current prevention approaches work within a politics of disgust and exclusion to maintain the socially constructed binaries of healthy/sick, valuable/resentful citizens, which have continued to cripple progress in the way of a more inclusive, egalitarian, and compassionate healthcare politics and system.

Moreover, these recommendations work to dispel the myth that “once a person becomes aware of their HIV-positive status, [that] that person automatically acquires the complex skills required for effective communication, decision-making and taking action around HIV transmission risk” (GNP+ 9). If one thing is made clear throughout this policy framework, it is that PLWHA are as human as the rest of us, that simply acquiring a disease and taking on its consequent identity does not mean that PLWHA magically understand its causes and effects, or that they can magically speak and become great educators on the subject. Rather, the GNP+ framework illustrates the fact that HIV/AIDS is a complex disease with various and diverse causes and effects, and that even if one comes to acquire the disease, that there exist a host of social, political and economic factors which can potentially hinder their ability to take action or become educated on the subject.

Lastly, the GNP+ policy framework combats the notion that we can effectively “end the epidemic” from an approach that individualizes responsibility. Parting from
current practices and policies that tend to blame PLWHA for their undesirable health status (whether this is because of their resented and “disgusting” sexual practices and behaviors, related to the criminal status of injection drug use, or any other of a host of sociopolitical factors that contribute to HIV/AIDS-related stigma and discrimination),
the GNP+ policy framework urges us to work towards a framework of shared responsibility. According to GNP+,

‘shared responsibility’ for HIV prevention is about recognising the role that broader social determinants of health and dignity play in human and sexual behavior. Firstly, it reinforces the concept that everyone is responsible for his or her health and should take steps to protect it. Thus, though people aware they are living with HIV know they have an ethical responsibility to avoid infecting another person, each individual shares the responsibility to avoid infection. Secondly, Positive Health, Dignity and Prevention creates an environment for HIV prevention beyond the individual—to include everyone regardless of their HIV status or proximity to the HIV epidemic. Sexual partners of people living with HIV, families, communities, civil society, the public and private section, the media, donor and multilateral agencies such as the UN all share in the responsibility to prevent new HIV infections (GNP+ 15)

Importantly, such a “shared responsibility” framework is directly in line with my notion of a more respectful and compassionate healthcare politics and system. Such a framework moves us away from the approach of individualizing responsibility on the order of blame for disease acquisition and transmission, maintaining and reinforcing HIV/AIDS-related stigma and discrimination, and moves us to the much needed conclusion that in order for us to overcome this struggle, we must all be in it together. While only so many individuals acquire and transmit HIV/AIDS every year, our current healthcare practices and policies have kept us from effectively reducing these numbers to zero in recent years, as our progress has stalled out despite continual watershed scientific breakthroughs in HIV/AIDS treatment and prevention practices. As is the case, we need to move towards a framework of shared responsibility – a framework that centers upon our shared (yet differentially experienced) vulnerability
as human beings – as an incentive for advocacy and mobilization efforts that can help to pick up the slack and get us back on track for zero new infections, zero cases of transmission, and, eventually, zero cases of HIV/AIDS period.

Using these central tenets as the building blocks towards a more compassionate and respectful healthcare politics, GNP+ details a host a policy recommendations moving forward. Among these, the framework recommends “the development, implementation, and monitoring and evaluation of all policies and programmes affecting people living with HIV should include—and ideally be led by—them” (GNP+ 11). Citing an April 2009 international technical consultation on HIV/AIDS in Tunisia, GNP+ states that participants agreed that policies and programs that are designed and implemented with the meaningful involvement of people living with HIV, [that] treat people living with HIV humanely and with dignity, [that] provide people with knowledge, skills, social and legal support, and [that] focus on the holistic health and related needs of people living with HIV “are more likely to be accepted and implemented, and will be more effective than existing programmes that narrowly focus on preventing new infections” (GNP+ 10). Accordingly, the GNP+ framework advocates more adequate and comprehensive engagement on the part of PLWHA in all steps of the policymaking process. Parallel to my notions of more respectful healthcare politics and practices, such a recommendation recognizes the vital experience and input PLWHA have to offer as individuals who live “the disease”, as individuals with diverse needs and interests to be fulfilled, and as individuals who are
equally impacted by – and who have an equal stake in – the development of comprehensive HIV/AIDS healthcare policy.

Another recommendation of the GNP+ framework is that healthcare legislation more adequately address

a range of factors that undermine health and dignity, including: poverty and food insecurity, lack of mental and psychosocial support, lack of educational opportunity, social exclusion, gender inequality, stigma and discrimination based on HIV-positive status, behaviours such as injecting drug use, sex work and/or sex between men, and identities such as being lesbian, gay, bisexual, transgender or intersex (GNP+ 15)

While many of these factors have been linked to increased risk for disease acquisition and transmission in recent years, issues such as decreased funding and the global economic recession, the capping of treatment and care programs, and drug stockouts have acted as disincentives towards embracing a more comprehensive treatment and prevention approach GNP+ 20). Due to decreased financial resources, it has been easy to stay our current course and not consider other additional approaches and programs that might significantly contribute to more effective HIV/AIDS treatment and prevention. Education on the causes and effects of social stigma and discrimination related to HIV/AIDS in general, as well as other notions such as comprehensive sex education in the classroom (i.e. not just “abstinence-only education,” but education that incorporates lessons on various and diverse sexual identities and preferences, etc.), condom distribution to youth – notions perceived to cost valuable time and resources – have been passed up because it is easier to just keep doing what we have been doing and forget about them (even if what we have been doing has stopped moving us forward towards progress). Unfortunately, without further addressing these contributing factors to our currently unsatisfactory progress in the case of HIV/AIDS,
we will fail to make further progress in “reaching zero.” Without addressing issues such as gender inequality, social exclusion, lack of access to stable housing, transportation, employment, and without thoroughly addressing and pledging to eliminate HIV/AIDS-related stigma and discrimination, we will continue to maintain and reinforce the socially destructive binaries of healthy/sick, valuable/resentful citizens, we will continue to see HIV/AIDS treatment and prevention services and programs plateau, and PLWHA will continue to suffer unnecessary harms from the disease. A more comprehensive HIV/AIDS policy framework – one that does not just make observations and recommendations based on the statistics and data, but one that moves beyond a purely “rational” approach to an approach that recognizes and seeks to explicitly address the confluence of social, political and economic factors that contribute to our currently disrespectful and exclusionary healthcare politics and system – is necessary to one day “reach zero” and “end the epidemic.”

Other recommendations that fall under this “comprehensive approach” umbrella include: removing all HIV-specific criminal laws and limiting prosecutions under non-HIV specific laws to intentional HIV transmission; removing criminal offences against men who have sex with men; removing criminal sanctions on sex between consenting adults, including in the context of sex work; allowing the provision of evidence-informed, harm reduction programs for people who use drugs; enacting privacy and anti-discrimination laws that protect people living with HIV; and enacting laws that ensure education, prevention, and treatment programs reach all people living with HIV, including children and adolescents born with HIV (GNP+ 30).
As far as HIV testing, treatment, and counseling go, GNP+ urges that the “individual living with HIV must have the right to choose if and when to start treatment”, that adherence counseling both before and after the initiation of antiretroviral therapy be available and recommended to patients, and that once treatment begins, access to antiretroviral therapy remain uninterrupted (GNP+ 33).

Further key policy recommendations include:

- Policies that support an enabling and non-discriminatory environment in which all people living with HIV—including members of marginalised populations such as injecting drug users, sex workers, men who have sex with men, and transgender people—are able to access health services and support on the same basis as their fellow citizens will ensure the best possible coverage of treatment on a clinically indicated needs basis, thus making the most of the prevention potential of treatment.

- HIV testing should always be voluntary, include full information regarding the medical and legal consequences of testing HIV-positive, and allow for anonymity during and after testing.

- Post-test HIV counseling should always be evidence-informed and include information on sexual, drug use and disclosure decision-making without coercion. Individuals who test HIV-positive should always have a fully informed choice if and when to commence antiretroviral treatment, which can be earlier (or later) than guidelines recommend based on clinical need.

- Where access to antiretroviral therapy is limited, individuals who require treatment based on clinical need according to local guidelines should always be prioritized over those who may receive treatment for prevention purposes (with the exception of prevention of vertical transmission).

- When there is a strong need or desire for a couple not to use condoms, ideally both the individual living with HIV, and his/her partner, should be counseled together regarding the impact of treatment on transmission risk.

- If antiretroviral therapy is to be taken as part of a combination prevention package for prevention purposes—particularly when it is taken earlier than currently recommended for health of the individual—the person living with HIV must be fully informed of, and agree to, the potential risks and benefits of such treatment on his/her health (GNP+ 33).

In order to achieve more equal and full inclusion of PLWHA in the decision-making process, the GNP+ policy framework further suggests: involving PLWHA as participants in focus groups or surveys; involving PLWHA in determining the research agenda, designing data collection tools, participating in data analysis, and contributing.
to conclusions and recommendations; training and working with peer researchers who are living with HIV; working with organizations and networks of people living with HIV; and ensuring a broad range of representation of PLWHA who are also members of different key populations (GNP+ 35).

The last set of recommendations GNP+ make relates to the incorporation of various evaluative techniques and measures to ensure the proper, efficient and beneficial implementation of HIV/AIDS healthcare policies and practices. Among these measures are:

- **THE PEOPLE LIVING WITH HIV STIGMA INDEX** – The People Living with HIV Stigma Index is a joint initiative of organizations that have worked together since 2004 to develop this survey, including the GNP+, ICW, IPPF, and UNAIDS.

- **The GIPA Report Card** – The GIPA Report Card (developed by GNP+, ICW, UNAIDS) identifies existing levels of the application of the GIPA principle in-country and provides insights on how the participation of people living with HIV can be made more meaningful.

- **Global Criminalisation Scan** – Since 2008, the Global Criminalisation Scan (developed by GNP+ and Regional Networks of people living with HIV) has been documenting existing legislation that criminalizes HIV non-disclosure, exposure, and transmission, as well as cases when these and non-HIV-specific laws have been used to prosecute individuals living with HIV. The aim of this in-depth research is to create a pool of knowledge that will inform advocacy plans and can be shared with other jurisdictions.

- **Human Rights Count!** – Human Rights Count! (developed by GNP+ and Regional Networks of people living with HIV) is a new evidence-gathering tool that aims to document cases of HIV-related human rights violations experienced by women, men, and excluded individuals living with HIV. The overall aim is to decrease the number of these human rights violations by using the information gathered to guide advocacy campaigns. (37)

- **Global Database on HIV-specific Travel and Residence Restrictions** – The Global Database on HIV-Specific Travel and Residence Restrictions provides updated information from 196 countries, on existing regulations denying entry or residency for people living with HIV, based on relevant country legislation.

- **Treatment Monitoring and Advocacy Project (TMAP)** – Launched in 2005 by the International Treatment Preparedness Coalition (ITPC), the TMAP identifies barriers to delivery of HIV services and holds national governments and global institutions accountable for improved efforts (GNP+ 36)
As is evident, the combination of recommendations laid out by the GNP+ framework is rather exhaustive, covering critical policy areas such as HIV/AIDS treatment, testing, serostatus disclosure, counseling, criminalizing statutes and a host of various other sociopolitical and economic factors which need to be addressed in order to move forward with a more inclusive, egalitarian and compassionate healthcare politics and system. Among these critical recommendations, the framework also does much in the way of advocating for a more respectful and socially conscious understanding of PLWHA. That is, the GNP+ framework is up-front and explicit in its recognition of PLWHA as not simply “vectors of new infections” – a notion that implies inhumanity, disgust and “threat” – but as fellow human beings and citizens deserving of respect and dignity as co-participants in and contributors to this nation. Moreover, the GNP+ framework stresses the fact that we must move towards a framework of shared responsibility as opposed to our current approach of individualizing responsibility in order to combat notions of “special treatment” and misleading difference between the character of PLWHA versus “the rest of us.” Such recommendations parallel and provide practical examples of the type of mutual respect we need in order to achieve a more inclusive, egalitarian and compassionate healthcare politics and system, and in order to finally “end the epidemic” and “reach zero.”

In addition to the GNP+ framework, another example of more respectful practices of engagement includes the GIPA principle cited above. According to the international HIV/AIDS organization UNAIDS, the “GIPA Principle was formalized
at the 1994 Paris AIDS Summit when 42 countries agreed to ‘support a greater involvement of people living with HIV at all…levels…and to…stimulate the creation of supportive political, legal and social environments’”, and was endorsed in 2001 by 189 UN member countries as a part of the Declaration of Commitment on HIV/AIDS (GIPA 1). UNAIDS asserts that the GIPA Principle’s primary focus is to realize “the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives” (GIPA 1). From this central tenet, we can see how, similar to the GNP+ policy framework, the GIPA Principle is dedicated to elevating the status of PLWHA to co-participants and even leaders in decision-making processes, highlighting the need to place greater value in the experiences and viewpoints generated by first-hand experience with HIV/AIDS. As was made clear in the GNP+ framework discussion, this PWLHA-centered approach is in stark contrast with current HIV/AIDS policies and practices that place significantly greater value on the epidemiological statistics and the interests of policymakers at the expense of undervaluing and excluding (whether formally or informally) the needs and experiences of PLWHA.

Importantly, the GIPA Principle takes us a step further. Not only does it emphasize the value and past success of proactive community engagement in interests that affect their well-being, but it also promotes the prerequisite breakdown of simplistic and false assumptions—e.g. that people without HIV/AIDS are solely “service providers” and that PLWHA are “service receivers”—in order to continue moving us closer to “reaching zero” (GIPA 1). This final tenet of the GIPA Principle
strongly parallels prior discussions of the disruptive consequences of socially
constructed binaries that lead to false notions of PLWHA being in need of “special
protections” and “special treatment.” Such notions can prove to be misleading and
disastrous for several reasons. For one, such a notion implies that people not living
with HIV/AIDS lead lives wholly absent of other forms of medical examination and
treatment—which is simply false. Secondly, it limits itself to the false premise that
medical examination, treatment and services are the only form of “services” we
receive. Such a notion wholly discounts the wide array of other forms of services we
both receive and provide to others in daily life—services as simple as taking care of a
friend or family member for the day, consoling a grieving friend or family member in
a time of loss, the emotional benefits sexual partners provide one another, having a car
wash clean your car, etc. Such notions, while they may seem ostensibly unrelated to
the HIV/AIDS epidemic, provide concrete examples of the various forms of service
provision/reception in daily life that we take for granted, and refute this false binary of
“service providers/service receivers.”

And, perhaps most importantly, incorrect distinctions such as this one between
PLWHA and people not living with HIV/AIDS continue to hinder attempts to buy into
the notion that we all share a common (yet differentially experienced) human
vulnerability, and make impossible the political solidarity of both PLWHA and non-
PLWHA behind this front. Such notions confine us to discriminatory justifications
based on the character and identity of PLWHA and those perceived to be “at-risk” for
HIV/AIDS – justifications that maintain our current exclusionary and unacceptable
approaches to thinking about and creating policies around HIV/AIDS – and deny the basic fact of life that we are all susceptible to various harms and illnesses (granted, some more than others, due to social and institutional conditions and/or barriers) at different points in our lives, and that this fact necessitates our sometimes asymmetrical provision/reception of services to/by fellow citizens. Such notions bind us to past and current sociopolitical approaches that have been unsuccessful and have stalled out in the struggle against HIV/AIDS, and must be forgotten and/or transformed in order to continue making progress towards effectively “ending the epidemic” and “reaching zero.”

Another key issue brought up by the GIPA Principle comes from the fact that while HIV/AIDS status disclosure can be empowering and healing processes for some, it can also reinforce prejudices against homosexuals, gender non-conformists, racial minorities, socioeconomically underserved communities, and others (GIPA 2). Accordingly, the GIPA Principle departs from the common misconception that serostatus disclosure or “coming out” is a prerequisite for decision-making involvement. Rather, the GIPA Principle supports and recommends “meaningful involvement,” not just tokenistic participation (GIPA 2). That is, that we ought to value more highly those individuals willing to dedicate their time, effort and resources to becoming change agents in the struggle against HIV/AIDS, rather than simply value the formal inclusion of as many “out” PLWHA as possible. This recommendation proceeds and is in line with many of the critiques brought up in the prior section on Inclusion and Democracy, and helps us to divest ourselves from any such notion that
only the “out, loud and proud” PLWHA have something to contribute in our common struggle for HIV/AIDS progress.

Proceeding these important perspective shifts in current approaches to HIV/AIDS debate and decision-making, UNAIDS’s GIPA Principle offers a series of policy recommendations and solutions based on various target audiences. These include:

Actions for Governments:

- Include GIPA in the National AIDS Plan; undertake a baseline survey for measuring GIPA and stigma and discrimination and include GIPA within the national monitoring and evaluation system.

- Enable people living with HIV to claim their rights and meet their responsibilities by creating a supportive legal and policy environment that also protects them from discrimination and violence.

- Strengthen public policy dialogue on HIV; create and promote educational and employment or income-generating opportunities; and promote the adoption of workplace policies in the formal and informal sectors, following the International Labor Organization recommendations.

- Support the creation and strengthening of organizations of people living with HIV in addressing infrastructure, governance, management, resource mobilization, accountability and staff skill building needs.

- Strengthen the capacity of people living with HIV who volunteer for leadership in public speaking and communication skills, in organizing and conducting policy advocacy, dialogue and negotiation, in programme design, and in monitoring and evaluation at international, regional, national and local levels.

- Provide resources to train, and engage or employ people living with HIV in self-care, in HIV prevention—particularly positive prevention—and in being a knowledgeable participant in personal treatment decisions (treatment literacy); as home-based care and community healthcare workers; in the practicalities and legal and social aspects of HIV and counselling; and in anti-stigma campaigns. Ensure that reasonable measures to facilitate employment of people living with HIV are taken.

- Ensure psycho-social support for persons living with HIV who, in revealing their status, may experience discrimination against themselves or their dependants.

- Promote better understanding of HIV-related vulnerabilities and the needs of people living with HIV in the community and workplace (GIPA 3).
Actions for organizations of people living with HIV:

- Organize and establish common ground with other organizations and networks of people living with HIV, and demand a place at decision-making tables.

- Ensure that the GIPA Principle is a living and practiced concept within organizations and that new, inclusive and diverse leadership, such as female, young people and other vulnerable population leadership, is nurtured.

- Encourage professionals, particularly people living with HIV, to become involved by offering their skills and services to organizations and networks of people living with HIV (GIPA 3)

Actions for wider civil society and the private sector:

- Mainstream HIV within organizations including the development and implementation of specific HIV workplace policies.

- Create procedures for implementing GIPA at all levels in the workplace including recruitment of skilled people living with HIV to boards and senior management.

- Commit and devote financial resources to organizational development, including leadership, management and governance, and capacity building of organizations and networks of people living with HIV.

- Work in partnership with other nongovernmental and government organizations and networks of people living with HIV on advocacy, service delivery and other relevant actions (GIPA 4)

Actions for international partners:

- Prioritize initiatives, supported by enhanced, predictable and continued funding, to build and sustain the capacity of organizations and networks in line with their self-identified needs.

- Promote efforts to fulfill the rights of people living with HIV, particularly women, young people and vulnerable populations.

- Promote good practice, strategic alliances and information exchanges between organizations and networks of people living with HIV within and across countries and particularly promote, fund and document South-South collaboration and mentoring.

- Harmonize, simplify and create more flexibility in donor/partner procedures to facilitate access to technical and financial resources for organizations and networks.

- Ensure that people living with HIV are included in the design of ethical research for new prevention technologies and the development of treatments (GIPA 4)

Highlighting just a couple of these recommendations, we see how such courses of action work within and bolster the type of inclusive, egalitarian deliberative democracy this project moves us towards. For example, under the section “Actions for
Governments”, the GIPA Principle not only highlights the need to get more PLWHA to decision-making tables, but also underscores the importance of making sure that those who desire to take on leadership roles in these arenas have the proper public speaking, communication, negotiation, program design and public advocacy skills required to make a positive and long-lasting impact on HIV/AIDS politics and policy. While more adequate and central inclusion of PLWHA in decision-making arenas is the vital and first step in the process, this recommendation hints at the fact – and attempts to proactively prevent the possibility that – once at the table, the voices of PLWHA will not once again be disregarded or undervalued on the basis of not knowing how to “talk politics” or “play the political game.” For, if we were able to get more PLWHA involved in the central process of decision-making, only to be subsequently excluded or rejected for a lack of “political know-how” (if you will), our efforts towards a more inclusive, egalitarian and compassionate healthcare politics would be all for naught.

Additionally, the GIPA Principle’s recommendation of promoting a “better understanding of HIV-related vulnerabilities and the needs of people living with HIV in the community and workplace” makes strong parallels with the type of inclusive, compassionate democratic politics this project moves us towards. Central to the notion of “reconstructing respect from the margins” is this process of social transformation in the ways in which we perceive and understand the lives and experiences of PLWHA. If we as a nation remain uneducated on HIV/AIDS – if we do not fully understand how or why there is such latent and ubiquitous HIV/AIDS-related stigma and
discrimination, if we do not know the ways in which HIV can be acquired, transmitted, treated and prevented, if we remain unaware of the relationships between poverty, food scarcity, employment, access to transportation, stable housing, lack of clean needles and readily-available condoms and the currently insufficient access of PLWHA to HIV/AIDS treatment and prevention services – then we will never be able to achieve the type of social transmogrification necessary to allow for more respectful and compassionate healthcare legislation, politics and practices. Becoming informed on these vital aspects of the HIV/AIDS “epidemic” is a necessary step towards achieving more inclusive, egalitarian, and compassionate democratic deliberative practices, and it beings with better understanding the needs, interests and values of PLWHA as they may differ from those of people without HIV/AIDS.

In sum, the above recommendations from both the GNP+ framework and the GIPA Principle provide concrete examples of more respectful practices of – and approaches to – engaging PLWHA in the decision-making process. While these are not the only sources of policy recommendations for HIV/AIDS healthcare politics and practices moving forward, they do comprise a rather comprehensive list of some of the transformative building blocks that can help move us forward again in our fight to “end the epidemic.” Many of these recommendations also do not provide concrete examples of legislation in place that reveal the specific wording of more respectful language towards PLWHA that this project is advocating for. However, what is important to take away from these examples is that significant shifts in the
perspectives and ideologies of American citizens – both for those individuals currently engaged in the decision-making process as well as those outside of, yet still affected by, these arenas and institutions – are necessary before we begin to formulate policy and language that can take the shape of more inclusive, egalitarian and compassionate approaches to and practices of mutual respect within the grander scheme of healthcare politics.

Returning to Stone momentarily, we must remember that political reasoning, and, consequently, policy creation are “strategic portrayal for persuasion’s sake, and ultimately for policy’s sake” (Stone 9). Understanding this key fact of politics allows us to recognize how past discriminatory practices and their false or problematic justifications have led us to our current approach to resolving the HIV/AIDS epidemic. More importantly, however, understanding this basic fact allows us to realize that unless we change the reasoning and justifications behind policymakers’ actions first, that we cannot subsequently achieve the type of more respectful practices of democratic engagement and HIV/AIDS policies that we need to continue moving forward in our strides towards progress. Taking these changes one step at a time and fostering more inclusive and compassionate practices of engagement and mutual respect of PLWHA as change agents in decision-making arenas – while also always keeping our minds in the future and on the end goal of all our work and effort – is the way forward for our and future generations. While we can expect this to be an arduous and demanding task that will require the most from many of us in the process, we must maintain hope that an HIV/AIDS-free generation and eventually “ending the epidemic” are attainable and
necessary goals for our nation. And, perhaps most importantly, we must recognize that the social transformations to come in following years – the transformations that will radically alter how we think about, define, and engage in politics and decision-making arenas – will not only transition us towards a more respectful healthcare politics and system, but also will pave the way for more inclusive, egalitarian and compassionate practices and policies in other policy areas.
Reflections

Throughout the course of this project, my research of – and critical reflections on – current HIV/AIDS healthcare practices and politics have taught me many things. Returning back to the inspiration for this project, my summer internship experience with the HIV/AIDS advocacy organization provided me with an initial lens into the ways in which our current healthcare system and public health legislation inadequately serve and continually marginalize PLWHA. This insight provoked a deep personal desire to pursue further research and analysis of ruling healthcare laws and practices – such as the NHAS and the treatment of PLWHA and HIV/AIDS advocacy organizations in decision-making arenas – that has led to a series of critical reflections and reevaluations of democratic deliberative processes of inclusion and mutual respect. These considerations have led me to rethinking how, when and why a certain social issue becomes elevated to national prominence, and who frames it as a social “problem”; rethinking how Americans perceive diversity, inclusion and vulnerability, and what alternative appeals to these notions might do in the way of fostering more egalitarian democratic deliberative environments; rethinking how certain socially constructed binaries are bolstered and reinforced through politics and legislation to maintain hegemonic, discriminatory or problematic justifications for exclusionary practices and processes; and attempting to argue for a new appeal to the concept of mutual respect—not as a moral value we ought to aspire to, but as a political tool and posture that we can practice and foster in decision-making arenas.
If I had to choose the most important lesson I have taken away from this project, it would be that reforming politics sometimes means starting from “the margins”—discerning what are the values, insights and concerns of the individuals who are most disproportionately negatively affected by ruling political practices and policies, and pushing these to the forefront of discussion. From all of the relevant sources that have contributed to and been a part of this project’s analysis—my summer internship and first-hand experience interacting with and getting to know new PLWHA on a day-to-day basis, the NHAS, the CDC, HHS, scholars who research and write on social risk, exposure, vulnerability, and HIV/AIDS politics, and so forth—one thing is evident: that PLWHA have as many unique and diverse experiences, values and opinions as the rest of us, and that their voices need to be heard. However, we must recognize the fact that when PLWHA are not included at the decision-making table, when they lack the proper social, economic, or political resources to make their voices heard, when they experience stigma and discrimination based upon their status as being HIV/AIDS+, or when they are unaware of the ways in which they can contribute to the HIV/AIDS debate and discussion—this demand becomes an impossible dream.

Scholar James Bohman – in his work Public Deliberation: Pluralism, Complexity, and Democracy – confirms this fact, asserting that deliberation without corrections for inequalities will always have such elitist tendencies in practice, favoring those who have greater cultural resources and who are more capable of imposing their own interests and values on others in the public arena (Bohman 111-112).

Importantly, Bohman’s comment gets us past the viewpoint of democracy as a series of discrete decision moments, and, rather, compels us to see democracy as a practice
through time. Through this lens, we able to better understand and connect how political decisions roll one into the next, how prior political actions or legislative measures (or lackthereof, for that matter) have consequently affected current and future decisions. In order to break this cycle, we must take action and correct for inequalities where they exist. In the case of HIV/AIDS this means, first and foremost, advocating for and reevaluating how we approach and practice the inclusion of PLWHA in decision-making and deliberative arenas. Accompanying this fact are a host of other issues that consequently must be addressed – HIV/AIDS-related stigma and discrimination, lack of stable housing, food scarcity, poverty, lack of transportation, sexual orientation/race/class-based discrimination, the need for more readily available condoms and sterile needs, fear of getting tested and being identified as seropositive, etc. – all which significantly and detrimentally affect PLWHA today.

As I have argued, I believe that part of the solution moving forward must come from “the margins”; that is, outside of the formal legislative arenas and institutions that we typically associate with politics. Progress on the issue of HIV/AIDS must be made through social transmogrifications that upset ruling hegemonic ideologies which further stratify our nation – posing us as adversaries in a battle against one another, rather than in a working together through a common struggle – and compel us to move towards a more compassionate and inclusive politics. The HIV/AIDS problem is not just one of public policy, but, in a broader sense, one of democracy—one of how we have formerly and in the future will come to treat, judge and incorporate PLWHA in decision-making arenas to move forward as a nation. And if we are able to succeed in
making these ideological transformations – if we are able to buy into the notion of a shared (yet differentially experienced) human vulnerability, if we are able to deconstruct and rid ourselves of the stigma and discrimination which we attach to HIV/AIDS, if we can recognize the value more inclusive and egalitarian deliberative practices and policies hold for an increasingly diverse nation – then we will finally be able to achieve the type of egalitarian, robust, compassionate healthcare system which we aspire to and which all Americans deserve as full and equal citizens of this nation.

Lastly, I would simply like to remark upon the fact that it is funny sometimes how things seem to come full-circle in life. As mentioned before, the inspiration for this thesis topic primarily stemmed from the experiences and interactions I had this past summer in Washington, DC, seeing and learning firsthand the ways in which PLWHA continue to be denied equal and full access to the healthcare services and treatment they need and deserve, and the ways in which policy language is produced to further marginalize and discriminate against these individuals. And now, after almost a full year’s research and investment in this project, I have the wonderful opportunity to return back to the same non-profit, doing similar HIV/AIDS legal advocacy work and to make a positive difference on the lives of PLWHA. Given this exciting news, it is my hope and fullest intention to return to the nation’s capitol with my newfound insight and thoughts on HIV/AIDS politics – and, more broadly, democratic practices of engagement and mutual respect – to continue acting as a leader and change agent in the name of progress, equality and social justice. While it
may be true that no one individual can transform an entire nation’s views or politics, I feel encouraged and empowered to continue on the path of my predecessors and current leaders in our struggle against the HIV/AIDS epidemic, hoping that my thoughts and actions will serve as an impetus towards chance and solidarity for others, revitalizing and resolidifying our efforts to continue making progress as a nation.


http://www.gnpplus.net/images/stories/PHDP/GNP_PHDP_ENG_V4ia_2.pdf (GNP+)


http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm (“HIV Surveillance Reports”)


http://www.whitehouse.gov/administration/eop/onap/nhas (ONAP)

http://www.whitehouse.gov/administration/eop/onap/nhas/activities (ONAP activities)


http://www.poz.com/articles/the_denver_principles_2267_15780.shtml (Denver Principles)

