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# HIV Education for Youth in Transition to Adulthood

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HIV Education for Youth in Transition to Adulthood

by

Peter E. Gamache

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
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## Glossary of Terms

**Acquired Immunodeficiency Syndrome (AIDS)** - An advanced stage of illness caused by the Human Immunodeficiency Virus (HIV). The case definition established by the Centers for Disease Control and Prevention (CDC) has evolved and currently includes opportunistic infections, conditions (e.g., wasting syndrome, dementia), and a depletion threshold for CD4+ cells.

**AIDS-Related Complex (ARC)** - Intermediate stage of HIV infection when symptoms are present but do not cumulatively meet the threshold CDC case definition of AIDS.

### Antiretroviral drug classes

**Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI)** - Suppresses HIV replication within host cells (i.e., after infection) by interfering with the reverse transcriptase enzyme. The non-nucleoside binds directly to reverse transcriptase and prevents ribonucleic acid (RNA) conversion to deoxyribonucleic acid (DNA).

**Nucleoside Reverse Transcriptase Inhibitor (NRTI)** - Suppresses HIV replication within host cells (i.e., after infection) by interfering with the reverse transcriptase enzyme. The nucleoside stops viral DNA synthesis since it lacks an element (3-hydroxyl group) needed for this synthesis to occur.

**Protease Inhibitor (PI)** - Suppresses HIV replication by preventing protease (an enzyme) from cutting the virus proteins into shorter segments, leaving the viral segments incomplete and unable to infect other cells.

**Fusion/entry inhibitor** - Bind to proteins on the surface of a HIV membrane (infectious agent) or CD4+ (uninfected cell). By preventing the connection, HIV is unable to pass and infect the CD4+ cell.

**Maturation inhibitor** - Impedes HIV replication by interfering with the last step of the HIV cycle before infection to other cells. A maturation inhibitor disrupts the processes that occur during the maturation process, such as the formation of an outer membrane.

**Integrase inhibitor** - Impedes HIV replication by blocking the integration of HIV DNA into the CD4+ host cell DNA.

**Gay-Related Immune Deficiency (GRID)** - A term predating HIV and AIDS that linked disease cause and effect to a specific population.

**Harm reduction** - Incremental, pragmatic efforts taken to lessen existing harmful behaviors or conditions. This approach contrasts with zero tolerance, abstinence-only efforts, incorporates surveillance data, and recognizes stages of change.

**Highly active antiretroviral therapy (HAART)** - Also called a drug "cocktail," HAART is a combination of three or more drugs (e.g., two NRTIs and a PI or NNRTI) to treat HIV.

**Human Immunodeficiency Virus (HIV)** - A retrovirus with genes comprised of ribonucleic acid (RNA). It is the disease that causes the advanced stage illness AIDS.

**HIV infection and replication** - The viral membrane surrounding HIV genetic material latches onto uninfected human cells where infection and replication occurs. The fusion and entry process involves a series of binding processes between a viral glycoprotein complex on the viral membrane and the CD4+ receptor and chemokine co-receptor (a protein) on the surface of an uninfected host cell. The following viral particles then enter the host cell: HIV ribonucleic acid (RNA), HIV reverse transcriptase (an enzyme), integrase (an enzyme), and other viral proteins. Once inside, reverse transcriptase converts viral RNA into viral DNA. The viral DNA then enters the host cell's nucleus, where it joins with the host cell DNA. The infected DNA then produces new RNA and viral proteins that exit the host cell to repeat this process, and the host cell dies. This replication cycle destroys billions of CD4+ T cells.

**HIV strain** - Four separate HIV strains have been identified and include HIV-1 (containing subgroups M or "major," N or "new," O or "outlier") and HIV-2, recombinant strains, and RBF 168. A person can be infected by multiple strains and become super-infected.

**HIV test** - Detection of HIV in serum (blood), saliva, or urine. An initial laboratory procedure called enzyme-linked immunosorbent assay (ELISA) tests for HIV antibodies. If the test is reactive (positive), a confirmatory Western Blot procedure tests for viral proteins that react with serum. Another HIV test, polymerase chain reaction (PCR), tests for viral genetic material (RNA and DNA fragments) in the blood. An oral HIV test is a noninvasive procedure that uses a swab to capture fluid (plasma) from within the mouth.

**Immune reconstitution syndrome (IRS)** - This condition, also called immune reconstitution inflammatory syndrome (IRIS), is characterized by an inflammatory response that worsens HIV symptoms during initial treatment with highly active antiretroviral therapy (HAART).

**Lipodystrophy** - This condition is a loss, gain, or redistribution of fat tissue or blood lipids that can result from HIV antiretroviral medication. Symptoms include sunken cheeks (facial wasting), legs, and thighs, in addition to pancreatitis, diabetes, and heart disease.

**Perinatal HIV infection** - Viral transmission from a HIV positive mother to a HIV negative child either pre-natally (e.g., virus crossing the placenta during pregnancy), during birth, or during breast-feeding.

**Seronegative** - A non-reactive (negative) serum reaction to a test for antibodies or other immune markers.

**Seropositive** - A reactive (positive) serum reaction to a test for antibodies or other immune markers.

**Side-effect** - Unintended symptoms or illnesses caused by medication. Side-effects caused by HIV antiretroviral medications can include diarrhea, facial wasting, high blood pressure, and organ damage.

**Window period** - The time between potential exposure to HIV and detection by an HIV test.

## **Abstract**

This dissertation investigated the role of Human Immunodeficiency Virus (HIV) stigma in program implementation. A case study design comprising qualitative methods provided in-depth, context-sensitive comparisons of adult educator ( $n = 8$ ) and youth ( $n = 67$ ) perspectives among programs that provide HIV services and those that provide risk reduction services. Nearly half of the youth participants were male, 42% were female, and 6% identified as transgender. Two thirds of participants were Black or African American, one quarter of participants were Hispanic or Latino, and the average participant age was 19. Although program personnel from all youth service programs in this study are acutely aware of how HIV stigma detracts from HIV education, programs that provide HIV services address stigma differently from programs that provide at-risk services. HIV education differs by language, inclusion, and stigma experiences. Based on the research literature and the findings from this study, structural changes are needed to accurately address HIV stigma and improve educational effectiveness across youth programs.

## **Chapter 1: Background**

More than a quarter century after the rise of public awareness of Human Immunodeficiency Virus (HIV), adolescents remain a population vulnerable to HIV infection. Youth between the ages of 13 and 24 contract HIV more than at any time in the history of the United States epidemic (Centers for Disease Control and Prevention [CDC], 2008). These youth are born with HIV or acquire the disease through breastfeeding, sexual victimization, blood transfusion, or high-risk behaviors (variant barrier protection, injection drug use) (DiClemente et al., 2008; Ford & Norris, 1993; Fuller et al., 2002; Mayo Clinic, 2009; Molitor, Ruiz, Klausner, & McFarland, 2000; Ratelle et al., 2005; Tyler, Whitbeck, Hoyt, & Cauce, 2004).

Because of successful public-health programs, the most important remaining targets of public HIV-education programs involve sexual activity and injection drug use. Mother-to-child (perinatal) HIV transmission infects approximately 100 to 200 infants annually in the United States, a low rate due to universal HIV screening laws and policies for expectant mothers, and transfusion-related HIV infection occurs 18 to 27 estimated infectious donations per 12 million per year due to enhanced HIV antibody screening of blood donations since 1985 (CDC, 2007a; Lackritz et al., 1995; Schreiber, Busch, Kleinman, & Korelitz, 1996). The majority of new HIV infections in the U.S. are therefore through sexual contact and injection drug use.

Sexual activity among youth is frequent, and related health risks are compounded by substance abuse (Rotheram-Borus, O'Keefe, Kracker, & Foo, 2000).

According to CDC Youth Risk Behavioral Survey data, approximately 47% of high school students report having sexual intercourse and over 6% of all students report sexual intercourse younger than age 13 (CDC, 2006a). A summary study using national surveys and public health literature estimates nearly one half (9.1 million) of the total incidence of sexually transmitted infections (18.9 million) occur between ages 15 and 24 (Weinstock, Berman, & Cates, 2004). Overall, a third of the U.S. population (112 million) report using one or more illicit drugs at least once in their lifetime, but it is not all adult use (Bureau of Justice Statistics, 2008; Substance Abuse and Mental Health Services Administration [SAMHSA], 2007). Nearly 10% of youth ages 12-17 and 20% of youth ages 18-25 report current illicit drug use (SAMHSA, 2007). Prevalent substance abuse among U.S. high school students is directly and indirectly associated with sexual risk behaviors that include lack of condom use and multiple sexual partners (Lowry et al., 1994). An estimated 7,761 young people with HIV were living with a diagnosis of the advanced-illness stage AIDS (Acquired Immunodeficiency Syndrome) in 2004, representing an increase of more than 40% since 2000 (CDC, 2008).

Barriers that confound efforts to educate youth about HIV include the beliefs among some youth that they are invincible or invulnerable to HIV infections (a personal determinant that has been described as a personal fable), myths such as outward symptoms solely indicating HIV infection (and inversely, lack of symptoms indicating non-infection), the belief that HIV is curable (or soon will be) or that drug treatment is readily available and tolerable, and myths that condoms do not work,

often break, allow HIV to pass through, and promote sexual activity (Baylor College of Medicine, 2006; Jack, 1989).

Breaking down these myths is more difficult when the myths are coadunate with stereotypes. As youth pass through stages of social expectations of adulthood that include taking responsibility for one's actions, establishing beliefs and values as part of one's identity, and taking on roles for family provision, they are exposed to varying attitudes about the likelihood of contracting HIV and perceptions of the types of people who have the disease (Arnett, 2001; Kittredge, 1991; Moore, Rosenthal, & Mitchell, 1996).

Social reactions to HIV and AIDS range from acceptance and support to fear and condemnation. In a national 1997 telephone survey using random digit dialing, nearly 29% of respondents agreed with the statement, "People with AIDS have gotten what they deserve" (Herek & Capitanio, 1999, p. 4; Kaiser Family Foundation [KFF], 2006a). This attribution of responsibility for disease is especially negative when infection is through sexual behavior or injection drug use since these transmission routes are frequently associated with moral or behavioral failures, social and political deviance, or the consequences of having a marginal social identity (Derlega, Sherburne, & Lewis, 1998; Nyblade, 2006; Weiner, 1993).

Misinformation surrounding HIV transmission also influences social reactions. Whether a holdover from the earliest transmission mysteries or a reinvention of local misconceptions, misinformation persists in diverse communities. Examples range from the semi-understandable such as mosquitoes passing infectious blood to the bizarre such as airborne or casual contact (Costin,

Page, Pietrzak, Kerr, & Symons, 2002; Dvorak, 2010; KFF, 2006a; Ritieni, Moskowitz, & Tholandi, 2008). Reports persist concerning people with HIV made to eat with disposable utensils, the avoidance of touch such as shaking hands, and fear of swimming in the same pool as someone with the disease (Lyon & D'Angelo, 2006; R. Sinnette, personal communication, January 12, 2010). Moral explanations (e.g., punishment from God) form additional perspectives with varying levels of acceptance and rejection (Overberg, 2010; Pieters, 1994).

### **Problem Statement**

HIV stigma is a particularly tenacious and enduring barrier to HIV education (Academy for Educational Development [AED], 2009; Avert, 2009; Brown, Macintyre, & Trujillo, 2003; Herek et al., 1998; Shapiro, 2005). Sociologists Link and Phelan (2001) describe stigma as the convergence of interrelated components that includes distinguishing and labeling differences, associating human differences with negative attributes (stereotypes), separating “us” from “them,” and the stigmatized experiencing discrimination and loss of status. If examined as a spoiler of identity, stigma functions to increase and maintain social distance, diminish value, dehumanize its targets as a path to human rights violations, and deny resources for those with infection (Goffman, 1963; Herek, 1999; World Health Organization/United Nations AIDS, 2001, 2005).

Injection drug use (IDU) is an especially high-risk activity for contracting HIV, and injection drug users are a stigmatized risk group. Sharing needles, a diminished immune system, and co-infection with hepatitis and other blood-borne pathogens markedly increase the susceptibility of HIV infection (Sulkowski &



Thomas, 2003). Since 1988 when the first syringe exchange program began in Tacoma, Washington, the concept of IDU harm reduction (incremental, pragmatic achievements) has been a major source of debate at the intersection of drug control and public health policymaking (Ball, 2007; Erickson, 1995).

Because of the close relationship between HIV transmission and IDU, AIDS has been described as a catalyst for promoting harm reduction strategies that can include a mix of prevention education, counseling, screening and testing, medical care, and the provision of supplies such as male/female condoms, alcohol pads, bleach, and sterile syringes (CDC, 2007b; Riley & O'Hare, 2000). While harm reduction receives support from the preponderance of research studies, in contrast to an abstinence-only curriculum, youth-serving programs emphasizing harm reduction face questions about age or developmental appropriateness (American Foundation for AIDS Research, 2007; Vlahov & Junge, 1998). Adapting services to the unique characteristics and specific circumstances of youth who are known to use drugs *already* is one logical approach, and national studies such as the National Household Survey on Drug Abuse and Drug Abuse Warning Network document drug use as young as age 12 (Johnson et al., 2003; SAMHSA, 2008, 2009).

Another prominent policy area concerning age appropriateness is secondary school public education to address comprehensive sexual health. While Congress reversed a 1989 federal funding ban on needle exchange, a step that Speaker of the House Pelosi (2009) termed a "victory for science and for public health," the weight of evidence supporting comprehensive public health education has yet to translate into widespread political support (Public Broadcasting Service [PBS], 2006a). From

1982 through the middle of the last decade, Congress appropriated more than \$1.5 billion dollars for abstinence-only or abstinence-until-marriage programs (Hampton, 2008). Similar to drug-abstinence and the familiar “Just say no!” campaign, proponents of abstinence-only sexual health education programs cite personal responsibility as the *only certain way* one can “avoid out-of-wedlock pregnancy, sexually transmitted diseases, and other associated health problems” (Santelli et al., 2006; Van Dyck, 1998, p. 1). Opponents of abstinence-only HIV education (including over 25 states refusing the funding) point to a lack of public support, a restrictive and exclusionary curriculum, and a lack of long-term sexual protection measures among youth (Bleakley, Hennesy, & Fishbein, 2006; Freking, 2008; Trenholm et al., 2007).

Unless youth receive comprehensive health education, communication among their peer networks, commercial media, and other dominant influences can lead to sexual norms and behaviors that are grounded in misinformation. Examples include peer sexual pressure and reputation-based popularity, gender expectations of manhood and womanhood related to sexuality, and individual risk-taking related to the acceptance of oral sex versus intercourse (Laub, Somera, Gowen, & Díaz, 1999; Prinstein, Meade, & Cohen, 2003). Media especially reinforce the belief that sexual expression is a rite of passage and is integral for what it means to become a man or woman. Advertising critic and media literacy educator Jean Kilbourne argues that media sells concepts of love and normalcy through sexual imagery (Kilbourne & Jhally, 1999; Kilbourne, Lazarus, & Wunderlich, 1979, 1987).

The package of HIV myths, stigma, and misinformation tied to sexual activity and injection drug use reinforce the existing barriers to effective education about sexual activity and substance abuse precisely among those who most need effective, pragmatic education. Avoidance of these issues due to discomfort, disbelief, or competing priorities neglects the substantial challenges youth experience as they progress to adulthood. As scientific advancements improve prevention, treatment, and care for the disease, the role of education is to replace mystery, panic, and the marginal social position of victims as it has with other socially destructive diseases and plagues (Doka, 1997).

Teachers can help youth better understand HIV in light of considerable institutional constraints. Accountability standards place pressure on teachers to limit topics and focus on requirements, and vital discussions about HIV are minimal (Meier & Wood, 2004; Nichols & Berliner, 2007). Whether it is appropriate for schools to address expansive social problems such as HIV is a longstanding educational debate (e.g., Kliebard, 2004; Tyack & Cuban, 1995), though a critical examination of how schools should best prepare students for adulthood is warranted given their frequency of failing or graduating—with HIV.

Thirty-five states and the District of Columbia mandate HIV education, though curricular content varies widely (KFF, 2010). Silin (1995) argues for an inversion of the HIV/AIDS curriculum that compartmentalizes and confines information about the disease within the health discipline. Silin maintains that when teachers use lesson plans that circumscribe what information can be taught, their approach is “far removed from the children’s lived experiences” (Silin, 1995, p. 62)

and does not reflect the “voice of the children” (Silin, 1995, p. 63). Educators within youth-serving human services programs face similar challenges connecting to students’ personal lives.

Educating youth who are disconnected from a system of care requires a more accurate understanding of their transmission risks. For example, several studies link illicit drug use and HIV with social ostracism (Bogart et al., 2008; Fuller, Ford, & Rudolph, 2009; Herek, Capitano, & Widaman, 2002, 2003), and youth who have more than one at-risk condition have a greater incentive to avoid self-identification, obfuscate risk factors, or underreport exposure frequency (Leigh & Stall, 1993). An inaccurate picture of these youth hinders efforts by HIV educators to tailor curriculum effectively or gain cultural and linguistic competence (Martinez & Van Buren, 2008). There are no research studies informing program implementation of HIV stigma reduction by comparing adult educator and youth perspectives among programs that provide HIV services and those that provide at-risk services, and this dissertation research seeks to build a foundation to address this gap.

### **Research Questions**

An investigation of how youth-serving human services programs and their clients define stigma and create a HIV-positive stigma reduction framework for those who are infected and those who are not includes the following research questions.

First, the following research question investigated the reactions to youth and others who are known to have HIV:

*Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

Directing this question toward program personnel through interviews provided the opportunity for an in-depth exploration of personal and social influences surrounding HIV stigma. In addition, interviewing program personnel allowed them to share their perspectives and experiences regarding what they believe works and what does not work when addressing youth regarding the topic of HIV. Directing this question to youth within group interviews allowed them to discuss how stigma operates inside and outside of the programs that serve them. This question holds important implications for outside influences program personnel cannot control but need to know, such as media, peer pressure, or evolving stereotypes.

After first identifying the factors that shape the silencing or addressing of HIV stigma, the following research question investigated the opportunities for program personnel to address it within the unique structures of their programs:

*How do individual program components (goals, objectives, and activities) address HIV-status stigma?*

This question was well-suited for in-depth interviews with program personnel to determine specific program resources and limitations. For example, some program components were misaligned with the critical needs of the client population, and providers' perspectives illustrated gaps and recommendations for addressing these needs. Directing this question to youth within group interviews allowed them to critique the activities programs use to address HIV stigma. The

relationship between these activities and the program goals and objectives illustrated several opportunities for realignment.

After establishing the factors shaping the silencing or addressing of HIV stigma and the potential for program personnel to address it within the specific contexts of their programs, the third research question investigated whether there are important differences in how programs connect with specific youth based on youth characteristics:

*How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?*

This question also spoke to the accuracy of program efforts, since the specificity of target populations by race, gender, sexual orientation, language, and other characteristics can be a challenge for personnel who do not have experience serving these groups. In-depth interviews explored priority populations considered most “at-risk,” program selection mechanisms, and the effect of specificity on program tailoring. Program personnel were asked to bring an example of an archival material (written or visual tool) they use to educate youth about HIV.

The purpose of collecting and analyzing archival materials was to evaluate the presence and framing of explicit curriculum messages used by program staff to educate clients. Program personnel serving youth at risk for or living with HIV use health promotion materials as educational tools in a number of ways such as placing pamphlets, booklets, one-sheets, and other take-away materials in public gathering spaces (a passive method) or handing these to program participants for discussion or counseling when conducting outreach (American Counseling Association, 2003;

CDC, 1999; Ross & Williams, 2002). The specific materials of interest to this study included those with depictions or descriptions of HIV or AIDS.

Since curriculum, outreach, and health promotion materials depicting people with HIV do not always resonate with youth, group interviews with youth allowed them to speak about how educational programs can best address HIV stigma through population-specific curricula. By gaining dual (provider-client) perspectives on this research question with the use of complimentary qualitative methods, a comparative analysis of their responses illustrated important differences between adult and youth perspectives.

The last research question is based on an understanding that youth involvement varies from one program to the next and can fall on different levels of what Hart describes as a ladder of participation (2002):

*How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?*

How participating youth have the resources, decision-making ability, and means to address HIV stigma within a program's structure may be similar to or different from the perspective of program personnel and youth. Since youth served by these programs may accept or reject efforts to address HIV stigma despite the best intentions of program personnel, it was especially important to ask both parties about receptiveness to educational efforts and opportunities to provide feedback.

Each of these research questions was central to understanding the structure of program implementation and the accuracy of HIV-status stigma efforts reflected

by dual (provider-client) perspectives. Investigating the relationship between outcomes of HIV stigma and the structure and response of the target programs required an in-depth exploration of specific program purposes, prioritization of risk groups, and program methods.

### **Pre-existing Researcher Perspectives**

Patton (2002) discusses the importance of explicitly disclosing pre-existing perspectives and the potential for bias when conducting research and interpreting meaning from data. Researcher bias is a particularly serious threat to the internal validity of qualitative inquiry in particular and is addressed by understanding the “lens” one brings to the study and preventing its influence (Maxwell, 2005, p. 108).

I was born in 1977 and was exposed to the earliest of HIV/AIDS education efforts in the Florida public school system. I have no memory of a disease-specific curriculum during elementary school (1982 through 1987), and my memories are of its discussion during middle school (1987 through 1991) in after-school specials, public service announcements, and news reports (see KFF, 2006b, for a media exposure timeline). Teachers presented condoms as a means to prevent HIV in eighth grade. Teachers also mentioned the disease during high school (1992 through 1996), though within science classes it was primarily a biological or medical topic (i.e., the entry of the virus into a cell and its replication). Within health classes, it was a topic related to communicable disease transmission modes (emphasizing “bodily fluids”). The educational model for the Pinellas County school district where I attended school was and remains abstinence-plus, where eighth graders continue to “learn about condoms in relation to disease prevention...[and]



high school students receive information on family planning as it relates to ‘future healthy behavior’” overall (Matus, Bousquet, & Winchester, 2008, p. 1).

I bring the following assumptions to the study:

1. HIV stigma is continuing and damaging;
2. HIV stigma divides communities by race, gender, and sexual orientation (see Henkel, Brown, & Kalichman, 2008, for a related discussion); and
3. Framing people as at-risk or high-risk for HIV in widely disseminated media can have unintended, stigmatizing consequences (see Wellings & Macdowall, 2000, for a related discussion).

I have worked as a program evaluator and researcher for several non-profits focusing on advancing effective prevention, care, and support for people living with or at risk for HIV/AIDS. I also provide informative case studies to the health and education fields by conducting interviews with program personnel and group interviews with youth to reconcile their suggestions for accurate program identification and implementation when addressing youth and HIV stigma.

My passion for HIV education for youth in transition to adulthood stems from having friends who have died from the disease, experiencing trauma related to nearly becoming infected, and caring for friends and community members who are HIV positive. When reflecting at AIDS vigils, I think of those who died of the disease as lost contributors to our lives. Surrounded by diverse survivors by age, race, gender, sexual orientation, and many other characteristics, I hope for a wide-spread realization that people need to cross through their essentialism to collectively address HIV and AIDS.

Four months after the severance of a long-term relationship, my former partner tested positive for HIV. Not knowing if I may have been exposed to the disease prior to my relationship ending, in addition to undergoing testing, waiting, and re-testing until an extended "window period" closed, I found myself in the very situation I had advocated and educated to others to prevent. Despite having transported and waited with friends who were fearful about going to the health department to receive their HIV test, I gained a deeper sense of empathy and a deeper appreciation for my personal network comprising HIV negative and HIV positive people who provided understanding and comfort during this difficult time. Two friends in particular helped me understand my own experience with HIV stigma. One who provided HIV testing and counseling told me that some of the people who tested positive later said that it was the best thing that could have happened, since the diagnosis made them realize the need to focus on healthy living and preventing the spread of the disease through advocacy (T. Lee, personal communication, April 14, 2008). I gained humility when I stopped to reflect on my complaints about potentially having the disease to a friend who is HIV positive. With the help of my support network, I consider my HIV negative status an educational opportunity and know that I would have reached the same conclusion had I become HIV positive.

## **Chapter Two: Review of the Literature**

### **Introduction**

The first chapter provided the background and rationale for addressing HIV stigma in program implementation. This chapter provides a review of the literature about HIV stigma, including stigma theories and the gaps that are particularly salient to informing program implementation.

### **Evolution of HIV Stigma**

Before the Human Immunodeficiency Virus (HIV) entered into public consciousness, a growing number of people in the late 1970s and early 1980s were hospitalized for a mononucleosis-like syndrome with a concatenation of symptoms (fever, weight loss, respiratory distress) and diagnoses (pneumocystis carinii pneumonia, oral thrush, Karposi's sarcoma) (Grmek, Maulitz, & Duffin, 1990). Retrospective studies date the incidence of the virus in the U.S. to 1968 (Robbins et al., 2003), though an emerging trend was not apparent until 1981 when the Centers for Disease Control reported five unusual cases of severe pneumonia in Los Angeles (CDC, 2001, 1981a), followed by a cluster of 26 highly unusual, rapidly degenerative cases in New York City, San Francisco, and Los Angeles (CDC, 1981b).

In the absence of an official term, descriptions of the disease linked cause and effect to a specific population. The first published headline in the New York Times read, "Rare Cancer Seen in 41 Homosexuals" following the CDC report (Altman,

1981), and ensuing reports depicted a new gay cancer, gay plague, or Gay-Related Immune Deficiency (GRID) (Gross, 2001). A growing case profile including heterosexuals, injection drug users, and hemophiliacs in concordance with refined hypotheses regarding modes of transmission led to alternate terms such as Acquired Community Immune Deficiency Syndrome (ACIDS) and Community Acquired Immune Deficiency Syndrome (CAIDS) (Shilts, 1987). Countries outside the U.S. would begin to know the disease by persistent informal or slang terms reflecting widespread disillusionment such as *tewo zamani* (i.e., “sickness of this generation”) and *nsikalileke* (i.e., “that which unto itself does not end”) (New York Times, 2009; Parker, Herdt, & Carballo, 1991; N. Welch, personal communication, January 17, 2010).

The term Acquired Immunodeficiency Syndrome (AIDS) officially emerged in 1982 (Grmek, Maulitz, & Duffin, 1990; Kher, 2003). HIV was discovered in 1983 by Françoise Barré-Sinoussi and Luc Montagnier (Nobel Foundation, 2008) with supportive evidence provided by Robert Gallo (Lasker Foundation, 1986). Gallo and Montagnier (2003) state that the “causative relation between HIV and AIDS was accepted by the scientific and medical community in 1984” (p. 2285). The definition of AIDS underwent several revisions to include opportunistic infections and to place a threshold on a vital white blood cell count (CD4+ T- lymphocytes), and the effect has been a shifting dividing line that “shape[s] how elites and the public conceive of people with AIDS,” which in turn “serve[s] to include and exclude different groups from policymakers’ consideration” (CDC, 1985, 1992; Donovan, 1996, p. 72). For example, the term AIDS-Related Complex (ARC) was used to differentiate

individuals in a gray area between HIV positive and symptomatic but not past the threshold CDC case definition that would confer disability and medical access (CDC, 1987; Crystal & Jackson, 1988).

AIDS and people with AIDS became a political lightning rod despite an evolving understanding of the disease and the use of clinical terms by public health officials and the medical community. Depictions of AIDS patients by sexual orientation contributed to the use of the disease as a political and social cudgel against gay men in particular, and there were social consequences for being associated with the disease (Herek, 1999; Poindexter, 1999). After a CDC (1983) report identified Haitians entering the United States as an at-risk group, the president of the Haitian Medical Association criticized the report as racist, leaving “a whole nation of people unduly alarmed and unfairly stigmatized” (Altman, 1983a, p. 1). Scientific evidence linking the origin of AIDS to Africa similarly sparked controversy at a time when proscriptions of avoidance, blame, and quarantine were advanced as means to protect the uninfected (L. Altman, 1985; D. Altman, 1986; Herek & Capitanio, 1999; Kanki, Alroy, & Essex, 1985; Wilton, 1996). A national poll by the Los Angeles Times in 1985 found large percentages of respondents favored quarantine (51%), identity cards (48%), and tattooing (15%) for AIDS patients (Associated Press, 1985).

The framing of the disease within media reports yields insights into how people who carry it were depicted. Table 1 illustrates frequency counts of key terms associated with HIV/AIDS according to LexisNexis Academic and ProQuest

Newspaper database searches of major English-language U.S. publications from 1981 through 1985.

Table 1

*Major Media use of Key Terms Associated with HIV/AIDS, 1981 through 1985*

<i>Search Term</i>	<i>Frequency</i>
HIV or AIDS + killer	70
HIV or AIDS + threat	145
HIV or AIDS + deadly	195
HIV or AIDS + suffer	267
HIV or AIDS + victim	596

*Note.* Search parameters for LexisNexis Academic and ProQuest Newspaper databases = major U.S. publications between June 1, 1981, and December 31, 1985, English language.

Media in the early to mid 1980s frequently framed HIV/AIDS with grave and menacing language. For example, it was described as a *relentless* and *powerful* killer that *strikes* people down (Gellman, 1983, p. 1; Seligmann, Gosnell, & Raine, 1984, p. 50; Seligmann, Hager, & Seward, 1984, p. 101). As a life-threatening condition, it allegedly spurred threats of lawsuits, economic collapse, and calamitous health of the nation. Crisis and war-oriented language weave through these descriptors, where the infected were *forced* out of employment, hospitals were *forced* to admit AIDS patients, and schools were *forced* to re-enroll infected children who had been expelled (Germani, 1985, p. 3; Parisi, 1985, p. 5; Sullivan, 1985, p. 1). Modern medicine was ultimately called upon to *conquer* it in *battle* (Altman, 1984, p. 1; Boffey, 1985, p. 16).

In contrast to these oppositional themes were depictions of AIDS suffering and victimization. Facing symptoms, discrimination, or death, victims were said to “waste away,” vulnerable to its “tragic” and “debilitating” effects (Altman, 1983b, p. 3; Engel, 1985, p. 1; Schwartz, 1985, p. 23; Seligmann, Gosnell, Coppola, & Hager, 1983, p. 74). An example of early cachectic AIDS imagery is a photograph of Ken Meeks in 1986 with Karposi’s sarcoma lesions (Reininger, 1986, 1988, 2006). Justification of physical segregation of these patients into AIDS hospitals, wards, or dedicated units included fears of contamination (i.e., to other patients and from healthcare practitioners’ refusal to treat) as well as the need for medical specialization (Bayer, 1988).



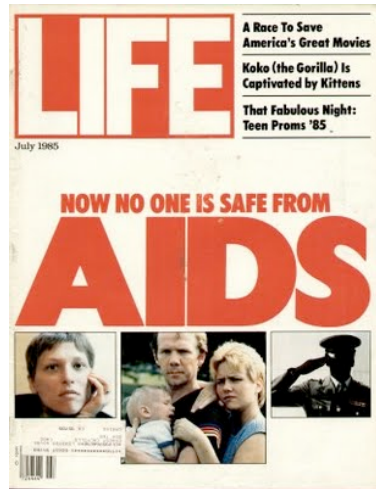
*Figure 1.* Depiction of Ken Meeks with Karposi’s Sarcoma. From “How AIDS changed America” by David J. Jefferson, 2006, Newsweek, p. 36-41. Copyright 2006 by Contact Press Images. This image contains copyrighted material that has not been specifically authorized by the copyright owner. Peter Gamache is making this material available for the purpose of education. This constitutes ‘fair use’ of the copyrighted material provided in section 107 of US Copyright Law. In accordance with Title 17 U.S.C. Section 107, this material is distributed without profit for educational purposes.

The contamination of the blood supply was a source of additional stigma and blame, surrounded by opposing commercial, public health, and public relations positions held by the Centers for Disease Control (CDC), U.S. Food and Drug Administration (FDA), National Institutes of Health (NIH), American Red Cross, American Association of Blood Banks, National Hemophilia Foundation, Pharmaceutical Manufacturers Association, and National Gay Task Force (Shilts, 1987). Dr. Bruce Voeller of the National Gay Task Force said, “You’ll stigmatize at the time of a major civil rights movement a whole group, only a tiny fraction of whom qualify as the problem” (Shilts, 1987, p. 222). Blood banks began banning gay male donations in 1983 with a screening question, “From 1977 to the present, have you had sexual contact with another male, even once?” (American Association of Blood Banks, 2009). This lifelong ban remains in effect for gay men regardless of sexual inactivity, long-term sero-negative confirmation, and increasing heterosexual transmission rates (FDA, 2009a; Johnson, 2010; Kerry, 2010).

Poindexter (1999) observes a shift in the social and political positioning of the disease with the introduction of the label “innocent victims” that included children, hemophiliacs, and heterosexual women (p. 38). One prominent example is Ryan White, a 14-year old who contracted the disease through blood transfusion, who was banned from his school in 1984 and was the subject of multiple news reports documenting prejudicial treatment (insults shouted at him, physical segregation, and vandalization of his family’s property, including a bullet shot through the front window of his home—see Barron, 1986; Johnson, 1990; Reagan, 1990; R. White, 1991, J. White, 1998). A headline reading “No one is safe from AIDS”



above a woman, a family, and a soldier on the July, 1985 cover of *Life* magazine in Figure 2 is emblematic of the reframing of AIDS as a social problem (Barnes & Hollister, 1985).



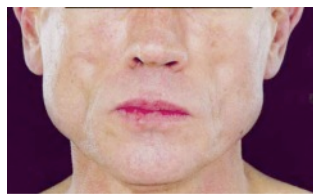
*Figure 2.* Depiction of AIDS as a social problem. From *Life*, 1985. Copyright 1985 by *Life*. This image contains copyrighted material that has not been specifically authorized by the copyright owner. Peter Gamache is making this material available for the purpose of education. This constitutes 'fair use' of the copyrighted material provided in section 107 of US Copyright Law. In accordance with Title 17 U.S.C. Section 107, this material is distributed without profit for educational purposes.

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Depictions of healthy people living with HIV did not emerge until antiretroviral drugs enabled the prevention of opportunistic infections. The first antiretroviral drug to treat HIV was Zidovudine (also known as the nucleoside reverse transcriptase inhibitor azidothymidine or AZT), which was approved by the U.S. Food and Drug Administration in March 1987 (FDA, 2009b). There are currently 32 medications among seven classes (FDA, 2009c), and combination therapy (typically three or more anti-HIV drugs from two or more classes) constitutes a drug "cocktail" called highly active antiretroviral therapy (HAART) that has been defined

in various ways according to revised treatment guidelines (U.S. Department of Health and Human Services, 2008).

Treatment of HIV involves managing side-effects that can occur in isolation (e.g., hair loss, diarrhea) or among multiple organ systems in tandem with an inflammatory response (e.g., immune reconstitution syndrome) (Belluck, 2010; DeSimone, Pomerantz, & Babinchak, 2000). A prominent side-effect of some HIV treatments is disfiguring lipodystrophy (also called lipoatrophy, the redistribution or loss of body tissue fat). Sunken cheeks, facial wrinkling, abdominal protrusion, and growth of a dorsocervical fat pad (buffalo hump) are several examples (Reynolds, Neidig, Wu, Gifford, & Holmes, 2006; Robinson, 2004). The visibility of these symptoms has been found to contribute to internalized stigma, resulting in depression and social withdrawal (Collins, Wagner, & Walmsley, 2000; Funk, Bressler, & Brissett, 2006).



*Figure 3.* Depiction of lipodystrophy. From “Lipodystrophy: What’s it look like?” by Anonymous, 2009. Copyright 2009 by AIDSmeds.com. This image contains copyrighted material that has not been specifically authorized by the copyright owner. Peter Gamache is making this material available for the purpose of education. This constitutes ‘fair use’ of the copyrighted material provided in section 107 of US Copyright Law. In accordance with Title 17 U.S.C. Section 107, this material is distributed without profit for educational purposes.

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Additional factors contributing to HIV stigma are widespread political discourse and policies, particularly in regard to disclosure requirements for having

the disease and mandatory testing. In a speech in 1987, President Ronald Reagan called for the U.S. Department of Health and Human Services “to add the AIDS virus to the list of contagious diseases for which immigrants and aliens seeking permanent residence in the United States can be denied entry” and “asked the Department of Justice to plan for testing all federal prisoners” (PBS, 2006b, p. 1).

As a longstanding opponent of the travel ban policy that subsequently went into effect, Congresswoman Barbara Lee clearly articulated the relationship between HIV stigma and policy: “The initial ban on travel and immigration for people living with HIV/AIDS was enacted in 1987 amid a climate of stigma, fear, and limited public understanding about how HIV was spread. People living with HIV/AIDS are required to publicly disclose their HIV status as a condition of entry, and if they are positive, their HIV status becomes a permanent part of their record, which may place them at further risk of discrimination” (Lee, 2007). In support of President Obama’s lifting of the ban in 2009, she wrote, “I believe that ending this policy. . . will aid in combating the stigma and discrimination against people living with HIV” (Congressional briefs: HIV/AIDS, health care and civil right, 2009).

Despite a high burden of the disease in correctional settings (Hammett, Harmon, & Rhodes, 2002) and CDC (2009a) recommendations for offering routine testing, political challenges have been acknowledged regarding needle exchange programs (Okie, 2007), condom distribution, and the availability of testing. As a result, mandated testing for HIV in prisons is in effect in 20 states (Rosen et al., 2009) and policies vary by jurisdiction regarding testing upon entry, during, and before release (Ruiz, 2008; Weinstein & Greenspan, 2003). Introducing the Stop

AIDS in Prison Act in 2006, Congresswoman Maxine Waters suggested that HIV stigma resulting from mandatory testing can pose dire health risks (Waters, 2006).

Punitive policy that entwines disease status and behavior is an outgrowth of social status stigma and reflects the tension between protecting the uninfected and institutionalizing risk-avoidance (Foucault, 1975). The majority of states have criminal statutes for HIV exposure that levy a misdemeanor or felony for knowing one's seropositive status and exposing others (Galletly & Pinkerton, 2004; Lambda Legal, 2009). Differentiating carelessness from intentional harm under the influence of drug or alcohol use is not an easy position for a judge or jury of one's peers, nor is deigning appropriate punishment for transmitting a disease that was once a "death sentence." Since the transformation of the disease into a chronic, manageable condition, has undisclosed transmission become less potent, thus requiring a reexamination of punitive policies?

The *correction* of the individual as a social problem does not resolve once someone with HIV infection receives a sentence of incarceration. According to the Bureau of Justice Statistics 2007-2008 data, 1.5% (20,075) of male inmates and 1.9% (1,912) of female inmates within the U.S. prison system have HIV (Maruschak & Beavers, 2010). When many of these inmates end their prison term, public health issues arise anew (Public Health Watch, 2006). While it is not known how many youth currently have HIV within the juvenile justice or adult prison systems, sexual victimization within these systems is frequent via youth-to-youth and staff-to-youth sexual activity, and these youth have histories of high-risk behaviors (Beck, Harrison, & Guerino, 2010; Widom & Hammett, 1996).

The previous examples sketch out the key issues in the continued evolution of HIV's media and political framing. The following sections will examine theoretical perspectives of HIV stigma enactment and development. The conclusion of this chapter comprises a discussion of theory and practice gaps, and the following chapter will present the research questions that will address these gaps.

### **HIV Stigma Theorized**

Theorists of HIV stigma give frequent credit to Goffman (1963), who conceptualized stigma as a spoiler of identity. After nearly 50 years since Goffman's text, theories of stigma in the professional and research literature have refined the inputs, processes, and outcomes of stigma. Its application to HIV stems from the work of HIV educators in community based organizations, medical practitioners, government agency personnel, and the leadership of psychologist Gregory Herek.

The majority of published literature on stigma appears in social science research journals in the disabilities, disease, substance abuse and mental health fields. Literature specific to HIV stigma among youth in transition to adulthood are primarily found in public health, medical, sociology, psychology, education, criminal justice, and HIV/AIDS journals. For this section of the literature review, I searched multiple databases: PubMed, Medline and PsycINFO (Ovid), Google Scholar, Cumulative Index to Nursing and Allied Health Literature (CINAHL), ProQuest dissertations & theses, and AIDS Education Global Information System [AEGiS]. The following keyword search terms and operands were entered into each of these databases: *Stigma + HIV* or *AIDS + Youth* (or *adolescent* or *child* or *pediatric*), and *Transition*. From the ISI Web of Knowledge and Google Scholar, the most commonly

cited, widely published expert panelists on HIV stigma are Gregory Herek (Brimlow, Cook, & Seaton, 2003; Herek, 1999; Herek et al., 1998; Herek, & Capitanio, 1999; Herek, Capitanio, & Widaman, 2002, 2003; Herek & Glunt, 1988), Richard G. Parker (Parker & Aggleton, 2003; Parker, Aggleton, Attawell, Pulerwitz, & Brown, 2002; Parker, Herdt, Carballo, 1991), John B. Pryor (AED, 2007; Pryor, Reeder, & Landau, 1999), John Capitanio (Capitanio & Herek, 1999), Peter Aggleton (Aggleton, Parker, & Maluwa, 2003), Angelo A. Alonzo (Alonzo & Reynolds, 1995), Nancy Reynolds (Reynolds, 2004), Betsy Fife (Fife, 2005; Fife, Scott, Fineberg, & Zwickl, 2008; Fife & Wright, 2000), Larry Brown (Brown, Lourie, & Pao, 2000; Brown, Macintyre, & Trujillo, 2003; Brown, Trujillo, & MacIntyre, 2001), Barbara E. Berger (Berger, Ferrans, & Lashley, 2001), and Maureen Lyon (Lyon & D'Angelo, 2001, 2006; Lyon, Silber, & D'Angelo, 1997; Lyon & Woodward, 2003). Among these experts, Drs. Brown and Lyon focus on youth.

A consensual conclusion of this literature is that HIV stigma is a permanent devaluation of an individual. Regardless of an outward appearance of illness, knowledge of an HIV positive diagnosis is enough to initiate avoidance and rejection. Controlling disclosure for fear of having a devalued self-image or experiencing harm becomes a concern for many people living with HIV. The HIV stigma theories primarily differ by causal mechanisms, temporal occurrence, and targets.

**Causal mechanisms.** The HIV stigma theories differ in how they ascribe causal mechanisms to nature versus nurture. Is it individual or social characteristics that primarily make one susceptible to HIV infection and stigma?

For example, Herek et al. (1998) point to cultural and individual causes. These authors maintain that negative social attitudes, discriminatory institutional policies, and poverty perpetuate HIV risks and responses, while individual fear and internalized stigma delay HIV testing and help-seeking. In contrast, Reynolds et al. (2006) focus on individual distress among HIV patients experiencing disfigurement related to their disease progression and medication side effects. They maintain that emotional and mental harm related to a negative self-image includes diminished social interactions, non-adherence to medication, and eating disorders.

Alonzo & Reynolds (1995) position stigma as resulting from an interaction between a biophysical condition and psychosocial and cultural beliefs. The authors view HIV as a socially constructed illness that interferes with interpersonal relations, is personalized and internalized, and progresses toward a convergence of late disease-stage signs and symptoms that require medical control and psychosocial coping. Parker and Aggleton (2003) characterize HIV stigma as a result of historical inequality in sociocultural, economic, and political relations. Framing HIV stigma as a social process, these authors view power and control as central agents for legitimizing status dominance. Fife and Wright (2000) focus on HIV associations (stereotypes) as the predominant sources of HIV stigma. Behavioral deviancy, victim blaming, and cultural stratification are determinants of internalized shame that increases self-deprecation and decreases feelings of personal control.

It is important to note that these authors do not position personal and social mechanisms of HIV stigma as mutually exclusive, but they emphasize different aspects of nature and nurture. Taken together, the response to the disease requires

a multi-faceted emphasis on reducing HIV stigma at the individual, community, and institutional levels.

**Temporal occurrence.** HIV stigma theories also differ by how they characterize the timing and sequencing of stigmatizing actions. These theories predominantly propose a linear relationship between the inputs and outcomes of stigma rather than multiple outcomes that continually become inputs.

Alonzo & Reynolds (1995) describe a trajectory of HIV stigma that begins with at-risk uncertainty (fear of exposure), followed by diagnosis (an altered identity), a latent phase between health and illness (concealment of disease), and a manifest phase (signs and symptoms leading to isolation). This phasing of HIV stigma follows a course of illness that is dynamic and where individual response options to control HIV stigma (selective concealment versus disclosure, denial versus coping, treatment adherence versus rejection) inevitably narrow. In contrast, Aggleton, Parker, and Maluwa (2003) conceptualize stigmatization as a process where socially unequal groups (by class, gender, race, and sexuality) are targets of exclusion and separation by negative views (wrongdoing especially linked to sex and drug use) and stereotypes (e.g., AIDS is a woman's disease, a disease of the poor, etc.).

Lyon and D'Angelo (2001) examined the developmental stage of children and the disclosure of their HIV positive status when they are deemed ready to understand and cope. Avoidance of parental disclosure to the HIV positive child, family, friends, and others is a result of fear of stigma and discrimination during a time of uncertain developmental appropriateness (below age 10). An earlier study



by Lyon, Silber, and D'Angelo (1997) found that difficult life circumstances (poverty, violence, abandonment) among HIV positive youth ages 12 to 21 are associated with avoidance and denial, relationship discomfort, and coping deficiencies. Receipt of an HIV positive diagnosis after prior, repeated trauma was not seen as an isolated, life-altering event but part of a spectrum of ongoing life challenges.

Brown, Macintyre, and Trujillo (2003) studied HIV stigma reduction interventions and concluded with the often-cited criticism that the evidence demonstrating positive results is limited in duration and scope (e.g., Garces, Thomas, & Currie, 2002; Goetz et al., 2009). Acknowledging the difficulty of HIV stigma research within high-stigma areas, the authors suggest that studies examine the relative, long-term contributions of multiple intervention components. Reductions in stigmatizing behavior include decreased fear, decreased negative attitudes and improved willingness to treat people living with HIV, and decreased distress and anxiety about HIV.

**Targets.** Herek and Glunt (1988) maintain that HIV and AIDS stigma readily attaches to marginalized groups. Sexual, racial, and ethnic minorities are framed as high-risk groups, while those who engage in IV drug use and sexual acts are influenced by social forces such as poverty, lack of education, and lack of social support. In comparison, Pryor, Reeder, and Landau (1999) describe how negative associations with HIV (death, illness, drug use) can contaminate ideas about HIV positive people regardless of their characteristics or how they acquired the disease. These authors propose a two-stage model where these negative associations leading to initial, prejudicial reactions can subside if stigmatizing individuals take the time

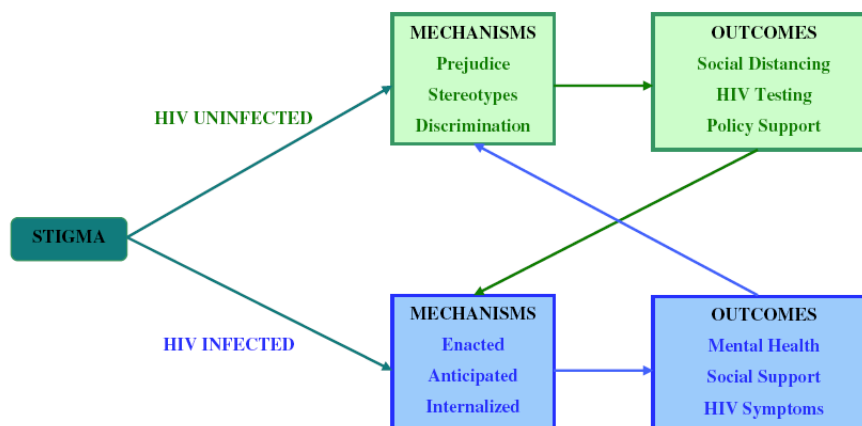
to think about their actions, evaluate the circumstances of the individual they are stigmatizing, and consider social standards where prejudice is not accepted.

Parker and Aggleton (2002) discuss the differential relationship between HIV status stigma and pre-existing social status differences. For example, women and men are blamed differently for spreading HIV when there is prevalent female sex work or assumptions about male promiscuity. HIV may also be seen as a White or minority disease depending on local cultural beliefs. Capitanio and Herek (1999) found that individuals strongly associate stigmatizing AIDS attitudes with injection drug users (the most stigmatized group) among Black and White Americans. The authors discovered a greater association between AIDS stigma and anti gay attitudes among Whites than Blacks. They theorize that this difference is due to different framing of the disease within these communities.

### **Recent Models and Program Guidance**

One conceptual model that has several useful characteristics and stands out among the theoretical literature is the *HIV Stigma Framework* (see Figure 4). Specifically, it differentiates the mechanisms and outcomes of HIV among uninfected and infected individuals and is designed to “understand and measure...the ways in which stigma is *experienced* by individuals who are HIV infected and those who are not” (Earnshaw & Chaudoir, 2009, p. 1090). These experiential constructs are particularly salient for this dissertation’s case study design comparing the perspectives of adult program personnel and the youth they serve within HIV service and at-risk programs.

This model proposes a relational explanation between the mechanisms and outcomes of HIV as opposed to a linear explanation proposed by commonly cited literature. The relational aspect of the *HIV Stigma Framework* is particularly salient to social network analysis, social support, and peer-education interventions designed to stop a social (communicable) disease. The model also proposes specific dimensions for addressing HIV. For example, youth and program personnel can explore how these dimensions interrelate, discuss their relative importance, and identify challenges to addressing them.



*Figure 4.* The HIV stigma framework. From “From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures” by Earnshaw, V. A., & Chaudoir, S. R., 2009, *AIDS and Behavior*. Copyright 2009 by Springer. Reprinted with permission.

Closely examining Figure 4, one can see that the model depicts HIV stigma as an exogenous variable that leads to differential mechanisms or responses to the disease among HIV uninfected and HIV infected individuals. For individuals who are not HIV positive, mechanisms for the devaluation of HIV individuals include

prejudice (negative emotions or feelings), stereotypes (negative generalizations), and discrimination (expressed prejudice) among those that are uninfected. These endogenous mechanisms interact with poor psychological, social, and physical outcomes experienced by HIV infected individuals and lead to social distancing, an avoidance of HIV testing, and a lack of policy support.

A relational model has some confirming evidence in rigorously-developed (i.e., psychometrically tested) measures of internalized stigma. Sayles et al. (2008) used factor analysis in developing a 28-item survey of internalized HIV stigma, and they found four items with high internal consistency reliability and item discrimination. These factors are stereotypes, disclosure concerns, social relationships, and self-acceptance. By asking whether youth who have HIV are stigmatized differently (stereotyped) by race, ethnicity, gender, or sexual orientation; whether youth would have concerns about disclosing they have HIV; and whether there is receptiveness to HIV education, this dissertation will explore the consequences of internalized HIV stigma.

In addition to theoretical and psychometrically tested measures of HIV stigma, official program guidance is useful for generating questions about program components that enable framing and an explicit curriculum to address HIV stigma. The *Elements of Successful HIV/AIDS Prevention Programs* from the CDC National Prevention Information Network (NPIN, 2009) upholds a set of common elements for HIV/AIDS programs that are linked to the CDC HIV strategic plan through 2010. According to this guidance, key themes among successful programs include community planning, the use of needs assessment and surveillance data (indicating

risk, incidence, and prevalence), and client evaluation of language and age-appropriateness. How these key themes apply to HIV stigma reduction in programs is a focal point of interest in this study. For example, program personnel responded to questions about needs assessment or other data they use to specify the number and type of clients served by their program. A follow-up question asked whether community planning informs how their program provides services. These questions are essential to understanding how programs gain information from their local community.

### **HIV Stigma Reduction**

Calls for a multi-level (biomedical, behavioral, and social) approach to HIV stigma reduction are frequent themes in the professional literature (Auerbach & Coates, 2000). For example, psychologists Herek and Glunt (1988) argue that both general public policy and specific education can address fears and overcome HIV stigma. They also suggest that educational programs approach AIDS not only with factual information but also with assurances to reduce anxiety and replace biases (i.e., cognitive heuristics). Specifically, AIDS education programs should have a curriculum that includes transmission risks (i.e., how it occurs and how it does not occur) *while* addressing stigma reduction.

Behavioral scientists DiClemente, Salazar, and Crosby (2007) also point out the importance of ecological approaches to HIV education. These authors examined the literature on individual-level behavioral intervention programs such as the CDC (2007c, 2009d) Diffusion of Effective Behavioral Interventions (DEBI) project and conclude that while these interventions are successful in the short term, their effects

significantly diminish over time. Through an ecological approach beyond enhancing individual-level pedagogical methods such as presentation, group discussion, role-play exercises, gaming, and problem solving, these authors suggest that behavioral HIV risk reduction behaviors can be sustained.

In sum, the role of education to reduce HIV stigma must take individual and macro-structural influences into account since stigma does not operate in isolation. International health educators Vandemoortele and Delamonica (2002) explain how stigma functions in concert with silence, shame, and superstition within a “climate of ignorance and illiteracy” (p. 7). This larger climate requires a broader, interdisciplinary view of personal *and* social influences rather than overemphasizing individual behaviors or social context.

### **Research Gaps**

Youth born between the mid 1980s and the latter part of the 1990s are in transition to adulthood during an evolving understanding of HIV/AIDS. The framing and public messages surrounding HIV/AIDS during the early years of the epidemic was overtly negative and grounded in an inability to control risks among specific infected populations (gay men, Haitians, African Americans, injection drug users) that could infect a larger population (hemophiliacs, heterosexuals). Programs operating since this time are reducing youth risks, and comparative implementation research with the use of a case study design in this area is nascent.

There are no research studies informing program implementation of HIV stigma reduction by comparing adult educator and youth perspectives among programs that provide HIV services and those that provide risk reduction services.

Because stigma is a formidable barrier to HIV education, this dissertation examined how youth-serving human service program personnel and their clients define and prioritize HIV stigma, describe its operation, and suggest ways that youth-serving programs can accurately address it within a high HIV prevalence, metropolitan area of the United States.

A comparative study illustrated differences between adult program staff and youth client perspectives, identified successful and unsuccessful educational approaches, and illustrated the limits and opportunities for a specified sample of programs. A case study design comprising complimentary qualitative methods was the best approach for gaining in-depth, context-sensitive, and experiential perspectives. The following chapter will detail the methodological and analytical rigor of this design (i.e., the structure), the limits of and considerations for implementing the design (i.e., the process), and the appropriateness of this design to answer a set of research questions (Donabedian, 1988).

## **Chapter Three: Methods**

### **Introduction**

The first two chapters provided the background of and literature review for stigma and HIV education for youth in transition to adulthood. This chapter describes the study's research methods for qualitative data collection, transformation, and analysis. Subsections detail the study design, research questions, study participants, data collection and management, and strategies for data analysis. The data collection instruments are located in the appendices.

### **Study Design**

The purpose of this research is to investigate how youth-serving human services programs and their clients define stigma and can create HIV-positive stigma reduction curricula for youth within programs that provide HIV services and those that provide risk reduction services. Since there is no comparative analysis of how HIV stigma operates according to adult personnel and the youth they serve within HIV service and at-risk programs (see Chapter 2), this implementation research addresses this gap by informing the youth-serving field with the use of a case study exploring how they can best address HIV stigma.

A case study design comprising qualitative methods structured the collection of primary data for this study. This design provided in-depth, context-sensitive comparisons of programs and individuals that can be combined with future studies



to form a basis for a national case study (Patton, 2002). Qualitative methods were appropriate to ascertain experiential, subjective perspectives of HIV stigma as an individual and social-relational construct that confers negative beliefs toward and within the infected (Goffman, 1963; Talley & Bettencourt, 2008). These methods included semi-structured interviews and group interviews that follow the established tradition of qualitative inquiry (Bernard, 2000; Lincoln & Guba, 1985).

HIV stigma is a phenomenon in need of greater understanding as it pertains to youth in transition to adulthood, and this research informs how youth-serving programs can best address it to help prevent HIV-related infection. Data collection focused on similarities and differences between the adult personnel and youth perspectives within programs that provide HIV services and those that provide risk reduction services. These settings connect youth to care and allow for an understanding of the role HIV stigma plays in program implementation. The case study design allows for an inductive examination of unique characteristics without a pre-determined expectation of results (Patton, 2002).

Tied to a lack of expectations is withholding of judgment of the participants' responses. For example, knowing that youth expressed incorrect views about HIV and people living with HIV raised an ethical issue for me as a researcher, since I was aware of my role in conducting a study and not an educational program intervention. While direct feedback to the participants was not part of this study, the aggregate findings from this dissertation will be shared with program personnel to address inaccuracies, misunderstandings, and myths.

The following research questions and procedures sections detail the achievement of redundancy, cross-data validity checks, and response consistency across qualitative methods (Patton, 2008).

### **Research Questions**

This section connects the research questions listed in chapter one with the collection of data exploring how youth-serving human services programs and their clients define stigma, how programs address stigma, and how programs can potentially create HIV-positive stigma reduction curricula.

The first research question was, *Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

I answered this question through interviews with program personnel, a data collection strategy that provided the opportunity for direct questions about program structures as well as an in-depth exploration of personal and social influences surrounding HIV stigma. In addition, interviewing program personnel allowed them to share their perspectives and experiences regarding what they believe worked and what did not work when addressing youth regarding the topic of HIV.

The second research question was, *How do individual program components (goals, objectives, and activities) address HIV-status stigma?*

This question was well-suited for in-depth interviews to determine the resources and limitations of programs that address youth and HIV stigma. For example, program components were misaligned with the critical needs of the client

population, and providers' perspectives illustrated gaps and recommendations for addressing these needs.

The third research question was, *How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?*

Answering this question required collecting perspectives of both program personnel and youth clients. More specifically, this question required collecting information in settings with different defined target clientele. Because the primary distinction in targeted clientele was between youth served by programs that provide HIV services and those that provide risk reduction services, staff interviews and group interviews were held at program locations. Staff interviews explored priority populations considered most at-risk, program selection mechanisms, and the effect of specificity on program tailoring. Program personnel had an opportunity (and were asked) to bring an example of an archival material (written or visual tool) that documents program structure either as program policy or in a *de facto* sense (e.g., material used to educate youth about HIV).

While program personnel knew what the program is *explicitly* supposed to teach, the research question also required exploring the reception of program intentions. Thus, this study included group interviews with youth. By gaining dual (provider-client) perspectives on this research question with the use of complimentary qualitative methods, a comparative analysis of their responses illustrated important differences between adult and youth perspectives.

The fourth research question was, *How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?*

This research question relied primarily on group interviews held with program clientele. Since youth served by these programs may reject efforts to address HIV stigma despite the best intentions of program personnel, it was especially important to ask both parties about receptiveness to educational efforts and opportunities to provide feedback. Youth involvement varied from one program to the next and fell on different levels of what Hart (2002) describes as a ladder of participation. Youth perspectives of how they have the resources, decision-making, and means to address HIV stigma within a program's structure were different from the perspectives of program personnel.

All of these research questions were central to understanding the structure of program implementation and the accuracy of HIV-status stigma efforts reflected by dual (provider-client) perspectives. Investigating the relationship between outcomes of HIV stigma and the structure and response of the target programs required an in-depth exploration of specific program purposes, prioritization of risk groups, and program methods.

### **Program Context**

Washington, D.C. provided a rich cultural setting to examine the role of Human Immunodeficiency Virus (HIV) stigma in program implementation. The nation's capital has a very high infection rate (3% of all residents), a majority-minority population, and many risk characteristics surrounding youth in transition

to adulthood (Bess, Doe, Green, & Terry, 2009; U.S. Census Bureau, 2010a; Fears, 2010; Vargas & Fears, 2009). The survival rate for a person living with HIV/AIDS in this area is very different depending on her or his race and ethnicity. Ninety percent of Whites and Hispanics survive HIV/AIDS at 10 years post-diagnosis, compared to 75% of Blacks at five years and 67% of Blacks at 10 years (Government of the District of Columbia, 2009).

Socioeconomic disparities in the District of Columbia were apparent by the people who were homeless lining the entrances to metro stations for safety and warmth during the preceding winter. Rows of bodies laid several blocks from multi-million dollar homes. Many youth are growing up in neighborhoods where piles of broken glass, cracked sidewalks, and trash lining streets typify social neglect and a lack of resources. Police sirens and yelling were also more frequently heard in these rather than wealthy neighborhoods. Compared to national averages, higher proportions of individuals (over 17% vs. nearly 13%) and families (over 14% vs. under 10%) are living below the federal poverty level within the District (U.S. Census Bureau, 2010b).

Ten youth service programs represent programs that are providing HIV and risk reduction services for youth. Five HIV and AIDS programs provide services such as HIV testing, primary medical care, and case management to HIV positive youth. Five risk reduction programs provide at-risk services to youth such as supportive housing (e.g., for run-aways), life skills for youth who are also parents (e.g., teen mothers), individual and family counseling, and outreach. These programs provide numerous opportunities for the health field to inform the education field and vice

versa. While there is a continuum of scholarly perspectives regarding qualitative inquiry that ranges from favoring intensive, longitudinal case studies with a small number of participants (e.g., Bourgois & Schonberg, 2007; Janesick, 1999) to a short-term, multi-site evaluation of a larger number of participants, this study included a cluster of programs to provide a depth of research experience and present findings for shorter-term program implementation.

I examined the mission statements of the ten agencies in Washington, D.C. where the programs operate. It is important to note that the word *community* appears 12 times among these agencies. Additional frequent terms include *serve* (14), *health* (5), *cultural* (5), and *education* (4). Specific youth population groups in these statements are *bisexual*, *gay*, *heterosexual*, *homeless*, *Latino*, *lesbian*, *run-aways*, *teen women and girls*, *transgender*, and *same-gender-loving*. Macro population groups in these statements include *culturally diverse communities*, *diverse urban community*, and *young people*.

## **Data Collection and Management**

### **Study participants.**

**Staff interviews.** Eight program staff members comprised the interview participant pool. Four worked for programs that provide HIV services for HIV-positive youth, and four worked for programs that provide risk reduction services for youth whose clients' HIV status is not explicitly identified. A list of participating program types whose administrators provided letters of support appear in Appendix A. Data reporting did not attribute any particular interview responses to either an individual or a specific program.

Inclusion criteria for these interview participants were the following: participants were aged 18 and above, had the ability to speak English to provide informed consent and respond to questions, and had direct experience working with youth for a minimum of six months as a service provider of either an HIV treatment program or at-risk youth program (e.g., juvenile justice, substance abuse, transitional living/homeless services). Participant titles included outreach worker, social worker, case manager, program manager, counselor, and HIV prevention, testing, or treatment specialist. All participants also had the ability to secure one hour either during their workday (with supervisor approval) or during non-scheduled work hours at their discretion, and they only participated in one interview.

Since each participant was a “unique informant with a unique perspective” (Patton, 2002, p. 347), participant homogeneity was not a required component of the interview design. Since the construct under investigation was HIV stigma among youth in transition to adulthood, the role of the participants (i.e., direct service providers to youth ages 13 to 24) was the primary inclusion criteria. Interview participants were not paid for their time, but they received the offer to be sent aggregate findings at the end of the study.

***Client group interviews.*** This study also included group interviews with youth participants from programs that provide HIV services and those that provide risk reduction services for youth (e.g., juvenile justice, substance abuse, or those in transitional living/homeless services). Program personnel recruited youth for a minimum of eight 60-minute group interviews divided into four group interviews

with clients served by programs that provide HIV services for HIV-positive youth and four group interviews with youth served by at-risk programs whose clients' HIV status is not explicitly identified. Data reporting did not attribute any particular interview responses to either an individual or program.

Inclusion criteria for the study were as follows: participants were between 13 and 24 years old, had the ability to read and speak English to participate in a consent process (either informed consent for adults or an assent process for minors), and were able to participate in the group interview. Each participant attended one group interview. With an upper bound of 10 participants per group, there were 80 potential participants to provide data. This maximum per-group size reflected the consideration that “small groups facilitate in-depth exploration of issues, since participants each have more time to share their experiences and perspectives” (Hughes & DuMont, 1993, p. 777).<sup>1</sup> The number of questions, amount of time, and moderator skill qualified the ability for smaller versus larger groups to focus on the research questions (Moreland, Levine, & Wingert, 1996; Posavac & Carey, 1997). With up to 10 primary research questions, one hour to collect data, and a skilled moderator who conducted this study, a group size of 10 participants allowed for several potential participants to be absent and still maintained the integrity (robustness) of the group interview design (Patton, 2002). Since 67 total youth participated out of a range of zero to 80, the resulting show rate was 84%.

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<sup>1</sup> Guidance for acceptable, optimal, or ideal ranges within the professional and research literature include 4-8 (Holloway, 2005), 5-8 (Krueger & Casey, 2009), 6-10 (Morgan & Scannell, 1998), and 8-12 (Stewart, Shamdasani, & Rook, 2007) participants per group.



Participant homogeneity by age range was another key component of the group interview design (Patton, 2002). Since the construct under investigation was HIV stigma among youth moving to adulthood, the age of participants was the primary inclusion criteria apart from client status and ranged from 13 to 24 years. This age range is consistent with the Centers for Disease Control and Prevention publications and fact sheets for HIV/AIDS among youth (e.g., CDC, 2008, 2009b, 2009c), is widely echoed in research publications and online reports from other federal agencies (e.g., NIDA, 2009), state departments of health, national HIV advocacy organizations, local community based organizations, boards of health, and medical societies, and is therefore a standard recognized age range among professionals in HIV research. Thirteen is also the age in many states when a minor can be tested for HIV without parental consent (Hartog, 1999; Jackson & Hafemeister, 2001), is the minimum, CDC (2006b) recommended age for routine HIV screening, and is the minimum age for FDA-approved HIV testing kits such as OraSure and OraQuick (FDA, 2002). The age range of the youth who participated in the study was 13 to 24.

In addition to age, youth participants were homogenous by program type. Four group interviews were initiated with youth who are served by programs that provide HIV services for HIV positive youth, and four separate groups were initiated with youth who are served by at-risk programs but whose clients' HIV status is not explicitly identified. Because the research questions focus on program structure and reception by targeted client group, the central division in groups focuses on that program client definition.

**Recruitment procedures.** Participating youth-serving human services programs agreed to help secure open-ended interviews with key informant program personnel in the following manner.

**Staff interviews.** Administrators (directors or managers) of programs that provide HIV services referred a minimum of four program personnel according to the aforementioned participant criteria who were interested in volunteering one hour of their time to discuss HIV stigma among youth. Administrators of programs serving youth at-risk for HIV (e.g., juvenile justice, substance abuse, transitional living/homeless outreach) similarly agreed to refer a minimum of four program personnel who were interested in volunteering to discuss HIV stigma among at-risk youth. To confer transparency regarding the nature and scope of inquiry, seek feedback, and procure approval, I shared the draft interview protocol with these administrators and created an online presentation (webinar) that explained the overall study design in the process of soliciting letters of support.

I sent individual emails and made phone contact with potential interviewees regarding the purpose, time, and preferred location of the interviews. I made a pre-interview prompt to bring archival health promotion materials (pamphlets, booklets, one-sheets, and other take-away items) that they use as educational tools in their programs. I collected one sample at the same time as the interview and did not pay to obtain these materials.

Program staff secured meeting room space for their individual interviews. I did not give participants the interview questions to review in advance, since the intention of the interview method was to gain open-ended, spontaneous responses

rather than preconceived answers (Patton, 2002). I omitted specific clients from the transcript who were incidentally mentioned during the course of the interviews to ensure the privacy of the youth these providers serve. I will destroy the recordings five years from the conclusion of the dissertation research study, and I will destroy the transcripts five years from the conclusion of the study.

***Client group interviews.*** Eight group interviews allowed participants to share their perspectives within a structured format that prompted a topical discussion on the issues surrounding HIV stigma. Flyers announced the purpose, time, and location of the groups to youth within HIV treatment programs and those that serve at-risk youth. Program staff secured meeting room space and then recruited participants through the flyers and verbal invitations. I instructed staff to schedule these groups in the same room immediately following an existing youth support group when possible. Ten participants attended each group, and I gave each participant a gift card worth \$25 for their time. I avoided tying grants or institutional funding sources to this dissertation to ensure autonomy, stability, and data retention.

To minimize socio-cultural barriers between a White, male researcher in a position of privilege who is approaching the top echelon of doctorate education and the youth within the group interviews who are from racial and ethnic minority populations, I asked program staff members to introduce me, I presented myself as a student just as they are, and I wore clothing similar to the program staff who work directly with youth (e.g., kaki pants and a t-shirt). I also wore solid colors to avoid

participant distractions from logos or words, and I used a back-pack to carry files and equipment as opposed to a briefcase.

I undertook a process to ensure understanding to gain informed consent for adult youth clients aged 18 to 24 and assent for minors aged 13 to 17 (i.e., provided clear explanations, sufficient time to carefully read the forms, checked for comprehension), provided an overall group interview demographics check-off form without names to collect information on age, gender, and race/ethnicity, and then facilitated, recorded, and transcribed these groups (Mack, Woodson, MacQueen, Guest, & Namey, 2005). I recorded key quotations illustrating group consensus or disagreement on a notepad during the group interviews. My direct involvement with facilitation and transcription enhanced the validity of the data, since third-party transcription professionals are unfamiliar with non-verbal expressions and gestures (e.g., nodding in agreement or disagreement).

To ensure participant privacy, I limited participant-level data collected on the group interview check-off form to age, gender, and race/ethnicity (see Appendix C for the group interview protocol). Since youth in the U.S. are increasingly multiracial and multiethnic, the race/ethnicity section of this form intentionally provided the opportunity to select "Other" and enter a write-in response (Nasser, 2010; Takaki, 1993; U.S. Census Bureau, 2010c). I did not collect names or other identifying characteristics, and I shuffled and separated the completed consent and assent forms in file folders.

I omitted all personal identifiers from the transcript that were mentioned during the group interviews. For each data collection method, I gained consent or

assent, recorded each 60-minute interview and group interview, took field notes, and then transcribed statements and notes verbatim except for identifying information. I will destroy the recordings five years from the conclusion of the dissertation research study, and I will destroy the transcripts five years from the conclusion of the study.

**Researcher Reflective Journal.** I kept field notes in a journal format to describe my interactions and relationships with the program staff, describe the number of staff members across agencies who meet the inclusion criteria (see Data Collection and Management - Study Participants), and record direct observations and impressions (e.g., fidelity to educational protocols). I sent drafts of the journal to committee members and key professional contacts to debrief and gain outside perspectives to the study experience. The use of a reflective journal effectively placed the researcher as a participant in the dissertation study.

## **Data Analysis**

**Coding method for interviews and group interview transcripts.** I used the qualitative software program Atlas.ti™ to organize and analyze the data (Muhr, 2004), and I took steps to partition text passages, code for redundancy, relatedness, and conceptual variation, and consolidate codes into themes that pertain to the research questions.

Step one consisted of loading the verbatim transcripts into Atlas.ti™ to create hermeneutic units (HUs). Once the HUs were created, I archived the rich text format (.rtf) transcript source files to prevent version conflicts and potential data corruption. I partitioned text passages within their respective HU and then grouped

according to the research question responses by respondent type and program type. I used an Atlas.ti™ memo to generate a list of potential codes (known as unattached *free codes*) for the analysis. Response frequency was the criterion for generating a free code, and I manually verified this list by employing the constant comparison method (see Table 2).

Table 2

*Free Codes*

Prevent*   early	Denial   disbelief	Unable   barrier   restrict*   limit*   can't
dead*   death   die   end*   expire	Don't care	Policy
Depress*	Ignorant	Confidential   privat*
Isolated   lonely   lost	Myth   story	Abstinence   say no
Stereotype   Judg*	Support   help	Condom
Prostitut*	Misinform*	Refer   link   connect
Slut   whore   sleep around   cheat*   promiscuous	Deny	Outreach   go
Gay   bisexual   homosexual	Blame	Test
Black   African American	Educate*	Help   support
White	Community   neighborhood   local	Peer   same
Hispanic   Latino   Latina	Treat	Community   network
Discriminat*   different   double-standard	Aware   know	Listen   talk   relate   tell   say   communicat*   discuss
Gossip   making fun   jokes   mock*   picked on   left out	Receptive*   open	Incentive   gift card
Nasty		Data   statistic   number
Overcome   reinvent   turn around   opportunity		Safe
Life   live   healthy   positive   strong		Young   youth   adolescent
Stigma   self-conscious		Girl   wom*
avoid*   push away		Boy   man   men
Fear   scared   afraid		Poverty   poor
Anger		Skinny   weight   appetite
		Sick
		Immigrat*
		Flexible   creative
		Alcohol*
		Close   hide
		Drug*   needles
		Homeless

Step two consisted of consolidating the code list to identify frequent response terms. I used the list of free codes to identify categories that represent a concept. For example, oak, pine, and maple would be free codes that represent the concept of a tree. Similarly, avoidance and degradation are free codes that represent the concept of stigma. These categories were useful for iterative consolidation.

A professional researcher (Patricia Gilliam, Ph.D., HIV clinician and qualitative research specialist) separately coded a sample of the individual interviews and group interviews to ensure coding reliability. Separate coding and inspection of the categories served as an important check on their redundancy, relatedness, and conceptual variation, and the independent selection of interviews controlled for unintentional bias that can potentially result from pre-selection.

Cohen's Kappa was a statistic used to assess the inter-rater reliability of coding qualitative, categorical variables (Cohen, 1960). Ranging from zero (incidental agreement) to one (perfect agreement), this non-parametric statistic provided a conservative index that accounted for agreements that occur by chance for each coding category. Kappa values ranging from 0.41 to 0.60 illustrate moderate agreement, while values above 0.80 represent nearly perfect agreement (Burla et al., 2008). To enhance the rigor of this study, we established a 0.80 kappa threshold for the two-rater coding process.

We independently coded one individual, adult program personnel interview and one youth group interview using an a priori coding framework and then compared these codes. The first kappa calculation was 0.48, indicating an unacceptable level of moderate agreement. We discussed operational definitions of



the codes and reviewed the specific areas of disagreement. For example, common sources of disagreement included *Myths* versus *Stigma* versus *Misinformation*. These related but distinctive concepts were in need of delineation and refinement.

After the major professor and a committee member overseeing this dissertation reviewed the adjustments to the a priori coding framework, the raters independently coded an additional adult program personnel interview and youth group interview. The kappa calculation was 0.83, indicating that we successfully reached a high level of agreement.

Chapter four provides text passages that contain rich examples of the relationship between the consolidated codes that pertain to the research questions, and Table 5 illustrates the final, 45-item coding framework.

**Coding method for archival materials.** As described earlier, I made a pre-interview prompt for program personnel to bring pamphlets, booklets, one-sheets, and other take-away materials that they use as educational tools in their programs. I collected one sample at the same time as the interview and did not pay to obtain these materials.

The archival materials provided supplemental information for the interviews and group interviews. Please see Appendix B for the detailed data abstraction tool that gathers descriptive data to allow for a discussion of the intended audience, publication and funding source, demographic depictions, and methods of communication. A sorting of the archival materials into these component variables allowed for an evaluation of the written and visual techniques used to inform or persuade youth.

**Limitations to internal validity.** This section discusses the threats to internal validity that I minimized to the extent possible for the interviews and group interviews. Threats to internal validity arise when inaccurate instrumentation and procedures influence the integrity of the study design (Fern, 2001; Stylianou, 2008). The primary issues with regard to internal validity for each qualitative research method in this study included the following:

1. Instrumentation;
2. Content and construct validity;
3. Subject clarity for participants; and
4. Social desirability response bias.

Strategies for increasing the finding's warrants and minimizing its threats included pilot-testing each method, following formal protocols, collecting and analyzing data within a time frame brief enough to assure accuracy of the information, and using a coding framework and analytic procedures that were transparent to outside observers (including the dissertation committee, USF institutional review board, and program administrators). Formal protocols are mechanisms to gain trust from program administrators and facilitate recruitment (Loue, 1995).

***Instrumentation.*** The individual interview and group interview protocols provided in Appendices A and B detail the instructions for implementing the respective instruments. Features within each included reminders for the researcher to verify all informed consent documents for the interviews were signed and filed, verify all assent documents for the group interviews were signed and filed,

commence recording, provide an introduction reiterating the purpose and overall expectations, check time versus progress at specified intervals, provide summative validity checks of participants' responses, and conclude with an open-ended invitation to share unstated discussions.

Differential response to prompts was a primary threat to internal validity. For example, it was estimated that some participants could provide long responses to a limited number of questions, stray from the topic, or provide minimal responses that are vague or unclear. These situations that threaten the integrity of the data were the primary factors that threatened internal validity and required moderator interruption and follow-up questions to probe for specificity. By pilot-testing the instruments through two individual interviews and two group interviews, I became familiar with the flow of the questions within time-constraints.

Participant response bias also may arise from withholding or limiting information. This limitation was minimized by introducing the overall topics that were asked, assuring confidentiality for the individual interviews and group interviews, providing participants with the human services background and experience of the investigator, and asking several warm-up questions about participants' background and experience to establish rapport.

It is noteworthy to acknowledge that some researchers question the appropriateness of group discussions to examine sensitive topics (e.g., Kaplowitz, 2000). However, this assertion has been countered as a "dangerous myth" that is based on assumptions regarding topics participants may find uncomfortable (Morgan, 1998, p. 50). Since HIV stigma is grounded in discomfort and characterized

by avoidance, an exploration of the topic in an intentionally structured group interview setting was appropriate (Sim, 1998). Furthermore, group interviews are successfully and increasingly used in a wide variety of disciplines to explore sensitive topics including drug abuse, sexual behavior, and a range of other disease conditions without adverse affect (Agar & MacDonald, 1995; Morgan, 1996; Robinson, 1999). The study demonstrated the willingness of participants to address the topic of HIV stigma.

An additional instrumentation threat to internal validity was variation in the use of probe questions. While probe questions are minimally allowable within a structured format (Patton, 2002), they can overtly adapt the instruments beyond their original structure. I minimized this threat to the integrity of the data by pilot-testing standard probe questions. Asking for additional details did not change the parameters of the questions but requested additional specificity from participants.

***Content and construct validity.*** Content validity (what is intended to be measured) and construct validity (the “measurement of an attribute or quality which is not operationally defined;” Cronbach & Meehl, 1955, p. 281) speak to the credibility or soundness of instrumentation (Hsieh & Shannon, 2005; Lincoln & Guba, 1985; Sireci, 1998). Current constructs of HIV stigma from the research and evaluation literature discussed in Chapter 2 were used to create the protocols and questions provided in Appendices A and B. Primary among these were the *HIV Stigma Framework* (Earnshaw & Chaudoir, 2009), psychometrically tested measures of internalized stigma (Sayles et al., 2008), and the *Elements of Successful HIV/AIDS*

*Prevention Programs* from the CDC National Prevention Information Network (NPIN, 2009).

***Subject clarity for participants.*** While the instruments contained constructs from the research and evaluation literature, there was always a risk that specific terminology may not have been accessible for all participants. To address the risk that study participants may have misunderstood questions or terms embedded in them, I asked several program staff who were not interviewed for this dissertation to review the interview protocols, questions, and item scales to ensure they were clearly understood, were logically sequential, and would provide maximal utility to program personnel when they conduct stigma reduction efforts (Silverman, Ricci, & Gunter, 1990). In addition, the pilot phase of this study that included two interviews and two group interviews provided a test of the instruments for clarity and responsiveness. The pilot revealed that two interview questions needed clarification, and there were no problems with the group interviews.

***Social desirability response bias.*** The fourth threat to validity was social desirability response bias on the part of respondents (Morgan, 1998). For example, it is possible that the interview discussions of program aspects related to HIV stigma may have yielded responses participants believed were socially acceptable or made their programs look outstanding (Podsakoff & Organ, 1986). This study minimized this threat by employing research procedures that ensured participant privacy before, during, and after data collection. While interviews are upheld as effective means to discuss sensitive topics such as HIV stigma, trust and rapport are essential elements of their success (Ruane, 2005). Despite my best efforts to gain trust and

rapport, the group interview participants discussing HIV stigma may have provided superficial responses they believed were socially desirable (Hollander, 2004). This study minimized this threat by employing research procedures that ensured participant confidentiality through each phase of data collection. In addition, I maintained neutral and non-judgmental reactions.

**Limit to external validity.** External validity is the extent to which researchers can apply the results of this study to other populations or contexts (Appleton, 1995; Lynch, Whitley, & Willis, 2000; Miles & Huberman, 1994; Ruane, 2005; Tobin & Begley, 2004). In qualitative research, researchers use the terms transferability or “fittingness” (Guba & Lincoln, 1981; also see Tashakkori & Teddlie, 1998).

Ongwuebuzie and Teddlie (2003) observe that the maximization of internal validity does not preclude threats to external validity, since findings can be valid but limited to the participants and context of the study. Since the samples for this research were purposive and narrowly focused on adult educator and youth perspectives among programs that provide HIV services and those that provide at-risk services within a high HIV prevalence population, a recognized limitation is a lack of transferability beyond participating programs (Freeman, 2006). However, Patton (2002) describes the ability to scale the case study design to include additional programs. The replication and sustainability of this study with successive case studies nationwide is an intentional outcome. Thus, this dissertation provides an essential building block for expansive inquiry, and the conclusions I draw from

this research will be limited to the participants and context as specifically described in Chapter 4.

**Reliability.** Internal reliability is concerned with sequential procedures' consistently testing the same constructs or phenomena of interest in the same way, while external reliability is concerned with the replication of findings in subsequent studies (LeCompte and Goetz, 1982). Valid and reliable data must therefore both be present to ensure the study has integrity, accuracy, and consistency. The methodologist Krippendorff (2004, p. 214) provides an illustration of the relationship between reliability and validity where a perfect target is at the intersection between the two, and increasing errors reduces both.

Procedural and instrumentation variations can result from inconsistent implementation of the protocols. The inconsistencies in the use of the instruments described previously (i.e., differential completion of the instruments within a 60-minute timeframe, withholding or limiting information, and variation in the use of probe questions) represented three threats to the internal validity or integrity of the data, but they also represented threats to internal reliability. Minimization of these threats included pilot-testing, assuring confidentiality for the individual interviews and group interviews, and establishing rapport.

Variations in membership posed an additional threat to the reliability of this study. Some of the group interviews may have comprised youth participants who had pre-existing relationships with other members of the group. For example, participants may have altered their responses among friends, though whether the effect was to share less or more is unknown and outside of the control of the

investigator. Guidance for conducting group interviews is unclear on how to obviate relationship dynamics that may affect the expression of views. However, there is a consensus on fostering inter-group dynamics to produce rich qualitative data, and these dynamics may have been enhanced by pre-existing relationships. In addition, since program evaluators such as Patton (2002) are successfully using group interviews for clients who have pre-existing relationships through programs, this study similarly recruited youth participants through programs.

Differing participant social and communication skills also can erode the reliability of group interaction. While group interviews allow for verbal discussion and hold the advantage of equating participants who may have widely disparate reading and writing skills, disparate participant maturity required moderation. Examples included participants who interrupted others, strayed from the topic, and attempted to dominate the discussion. I minimized this threat by using several techniques to enhance consistent participation. For example, I established expectations at the beginning of the group interview, revisited these expectations during the group, called upon quiet participants, and expanded or limited the timing of individual responses. In addition, I employed in-vivo summative checks (member checking) during every group interview session to ensure clarity and validated inter-group conclusions (Cohen & Crabtree, 2008).

### **Pilot Study**

A pilot study tested the structure and process of the case study design. I conducted two pilot interviews and two pilot group interviews to facilitate member-checking of the question structure (phrasing, sequencing, and missing topics),



timing (ability to complete all questions), and ability to address the topic of HIV stigma through a structured format. For this pilot, I gained consent for the interviews and either consent or assent for the group interviews as described for the dissertation data collection, provided an overall group interview demographics form without names to collect minimal demographics (age, gender, race/ethnicity), and then facilitated, recorded, and took extensive notes during the pilot.

Table 3 presents the pilot study group interview participants' gender, race/ethnicity, and age. While youth ages 13 to 24 and English language were the only specified demographic characteristics used for participant recruitment, the majority of participants were male, Black or African American, and between ages 19 to 21.

Table 3

*Pilot Group Interview Demographics*

<i>Gender</i>	<i>%</i>	<i>Race/Ethnicity</i>	<i>%</i>	<i>Age</i>	<i>%</i>
Male	63	Black or African American	89	13 to 15	32
Female	37	Hispanic or Latino	11	16 to 18	21
				19 to 21	47

Immediately following the one-hour interviews and group interviews, I asked participants the following questions:

1. Do you think that others who are similar to yourself will respond to the questions I asked?

2. Do any of the questions need to be changed to find out what others who are similar to yourself think?
3. Did you have the opportunity to talk about what is important to you regarding HIV stigma?
4. Are there questions that should be added/omitted?
5. Which questions did you need to think about the most/least?
6. Are there better ways that the questions could be asked?

Two days after the interviews with program personnel, these questions were repeated to determine if they had additional feedback for how the questions apply to their work. In addition, program staff who were not interviewed for this dissertation were asked to review the interview protocols, questions and item scales to ensure they are clearly understood, are logically sequential, and would provide maximal utility to program personnel when conducting stigma reduction efforts (Silverman, Ricci, & Gunter, 1990). Detailed notes were taken, and feedback was incorporated to refine the instruments.

The pilot revealed that two staff interview questions needed clarification and that there were no problems with the phrasing of questions for the group interviews. When I asked about what limits the ability of program personnel to address HIV stigma, two interviewees asked what I meant. I clarified the type of limit as an institutional limit. When I asked whether there are client needs that their program is unable to address, one participant asked what types of needs, and I clarified this as a need related to HIV. I learned from the group interviews that youth

are open and responsive to talking about HIV and that they use terms for HIV that the interviewed adults do not.

Following the pilot study, all dissertation data were collected during August 2010. During each day of data collection, I created a researcher reflection journal to provide context for the study. This journal illustrated observations of the local neighborhoods where programs operate, in addition to details regarding the logistics and data collection process.

Eight individual, one-hour interviews with program personnel and eight one-hour focus groups comprising 67 youth are complete. With up to 10 available seats per group interview, the resulting show rate was 84%. Given a heat index that exceeded 100 degrees on several days and intermittent rain showers, this rate is testament to the interpersonal skills of the program personnel who independently recruited youth to arrive at specific times and places. Many of these personnel experience high caseloads, administrative requirements, and the stress of uncertain funding. Their voluntary participation to assist with this dissertation above and beyond their duties is a reflection of their caring and concern regarding HIV education for youth. The youth spent time away from other activities to prioritize volunteering for the study, and they gathered to discuss a stigmatizing disease with similar age peers.

The interview inclusion criteria stipulating a minimum of six months employment reduced the available participant pool, since three additional adult program staff were willing to provide responses but did not meet this requirement. Many of the program administrators who facilitated recruitment cited funding

difficulties leading to staff furloughs, the conversion of line staff into intermittent program consultants, and new, part-time workers.

### **Participant Demographics**

Table 4 illustrates the 67 group interview participants' gender, race/ethnicity, and age. Nearly half of participants were male, 42% were female, and 6% identified as transgender. It is important to note that the self-identity of additional individuals who were potentially transgender was marked male or female on the data collection forms (see Gagne & Tewksbury, 1998 for a related discussion of conformity and gender passing). Two thirds of participants were Black or African American, a quarter were Hispanic or Latino, and the remaining nine percent indicated specific countries, mixed race, Asian, and American Indian or Alaska Native. The average participant age was 19, and the majority (68%) ranged from ages 16 to 21.

Table 4

#### *Group Interview Demographics*

<i>Gender</i>	<i>%</i>	<i>Race/Ethnicity</i>	<i>%</i>	<i>Age</i>	<i>%</i>
Male	52	Black or African American	66	13 to 15	11
Female	42	Hispanic or Latino	25	16 to 18	37
Transgender	6	Other	9	19 to 21	31
				22 to 24	21

## **Prior Relevant Researcher Experiences**

Having worked as a research faculty member of the University of South Florida for over eight years on multiple research and evaluation projects and a consultant for HIV/AIDS non-profits in Tampa, Florida and Washington, D.C., my experience with interviews and group interviews includes professional as well as graduate-research projects. Examples include the Pinellas County Needs Assessment that used public forums, group interviews and interviews (Giard & Gamache, 2005), an assessment of the mental health needs of children in the Florida child welfare system that used interviews (Paulson, Prince, & Gamache, 2007), the successful design and implementation of a group interview study of Spanish language health communication that used group interviews (Gamache & Callejas, 2008), an evaluation of a youth service program that used interviews and group interviews (Gamache, 2010a), and the generation of case studies from interviews of HIV program recipients for a Minority AIDS Initiative administered by the Health Resources and Services Administration (Gamache, 2010b, c). I am also certified in HIV/AIDS 500/501 Counseling, Testing and Referral Services, which is client-centered and meets the CDC and Florida Department of Health requirements for providers of HIV counseling and testing services (Rogers, 1995).

## **Chapter Four: Findings**

### **Introduction**

The previous chapters provided the background, literature review on stigma and HIV education for youth transitioning to adulthood, and methods for qualitative data collection, transformation, and analysis. This chapter describes the study's findings with subsections that detail each research question, participant response themes, and how the data link together.

### **Coding Framework Summary**

Table 5 provides a macro-analysis of responses to illustrate the major patterns of discussion within the individual and group interviews (see Appendix E for operational definitions). The major categories and response items supersede the free codes presented previously in Chapter 3 and include program barriers, current program components, and suggestions to address HIV, in addition to client barriers, views of HIV, and suggestions for clients to address HIV. The aggregate response theme frequencies within Table 5 guide the selection of what is reported in the rest of the chapter. Specific comparative analyses between adult program personnel and youth clients by program type are presented with illustrative quotations in a separate section that follows.

Table 5

*Aggregate Response Themes*

<i>Program Barriers to Address HIV</i>	<i>Current Program Components</i>	<i>Program Suggestions to Address HIV</i>
Curricular limitations ( <i>n</i> = 35)	Openness to discuss ( <i>n</i> = 35)	Curricular flexibility ( <i>n</i> = 54)
Capacity (no time/staff) ( <i>n</i> = 23)	Social support ( <i>n</i> = 23)	Developmental appropriateness ( <i>n</i> = 36)
Policy restrictions ( <i>n</i> = 14)	Informal client feedback ( <i>n</i> = 23)	Facilitator skill ( <i>n</i> = 24)
Confidentiality concerns ( <i>n</i> = 13)	Formal client feedback ( <i>n</i> = 19)	Community networking ( <i>n</i> = 23)
Personnel stigma ( <i>n</i> = 4)	Use of data ( <i>n</i> = 15)	Safe place ( <i>n</i> = 16)
	Condoms ( <i>n</i> = 14)	Condoms ( <i>n</i> = 11)
	Referrals ( <i>n</i> = 14)	Facilitator characteristics ( <i>n</i> = 14)
	Testing ( <i>n</i> = 14)	Client incentives ( <i>n</i> = 11)
	Lessons plans/curricula ( <i>n</i> = 13)	Peer education ( <i>n</i> = 26)
	Outreach ( <i>n</i> = 13)	
	Abstinence ( <i>n</i> = 9)	
	Community input ( <i>n</i> = 8)	
	Partner notification ( <i>n</i> = 3)	
<i>Client Barriers to Address HIV</i>	<i>Views of HIV</i>	<i>Client Suggestions to Address HIV</i>
Stigma ( <i>n</i> = 85)	Stereotypes ( <i>n</i> = 47)	Client awareness ( <i>n</i> = 45)
Misinformation ( <i>n</i> = 75)	Discrimination ( <i>n</i> = 45)	Client receptivity ( <i>n</i> = 24)
Cultural norms ( <i>n</i> = 62)	Death sentence ( <i>n</i> = 32)	Client-to-personnel trust ( <i>n</i> = 15)
Fear ( <i>n</i> = 38)	Preventative ( <i>n</i> = 17)	Client communication skills ( <i>n</i> = 12)
Lack of social support ( <i>n</i> = 29)	Second chance at life ( <i>n</i> = 16)	
Myths ( <i>n</i> = 27)	Hopeless ( <i>n</i> = 15)	
Denial ( <i>n</i> = 25)		
Self-blame ( <i>n</i> = 16)		
Negative treatment ( <i>n</i> = 15)		

The program barrier cited most often by adults and youth is limited curricula related to the scope and depth of information about HIV. Youth responses also reflected an awareness of this limitation. For example, a youth from an at-risk program said, "I just didn't like the way it was presented because it...just, really, it wasn't reality." Another youth from an HIV service program said, "It has to be something new and innovative. When you start talking about HIV, it's kind of like boring, I've already heard it. It's all the same."

Among all of the programs, the main program components to support HIV education for youth are maintaining openness to discussing HIV and providing social support. The adult program personnel and youth clients described having ongoing, informal conversations to feel comfortable and talk openly about how the program provides services, and the least frequently cited aspects of these programs included inviting community input and partner notification.

The program suggestion raised most often by adults and youth is curricular flexibility. Frequent examples of this flexibility include incorporating youth language and exploring concerns raised by youth that are tangential to formal, proscribed curricula. Developmental appropriateness concerning the best age to introduce HIV and related topics (sex, IV drug use) was also frequently discussed, yet there was no consensus on the best age. Responses spanned from as soon as children can walk and talk to age of sexual onset (earlier than puberty, at puberty) to high school age. The youth and adults frequently referred to their own experience learning about HIV in school, which followed a similar wide range. When asked about the age-appropriateness of HIV education, these respondents consistently referred to their



school grade levels and suggested for youth to receive this education younger than when they learned about it.

Among the client barriers to addressing HIV, adults and youth frequently discussed instances of stigma and misinformation surrounding the disease. Cultural norms among youth who believe they are invincible and either do not care or do not think about HIV or their risk of acquiring it were prevalent areas of discussion. For example, youth within one group discussed the following about youth partying: "You're at the club, you're really drunk, the next thing you know everyone who's with you, they're not even there anymore. You're thinking in the moment. You can pass by a pharmacy, go to a pharmacy to protect yourself [referring to purchasing condoms], but you're not thinking about that."

Additional barriers include fear of the disease and youth who have it. Youth in particular frequently cited negative treatment toward youth with HIV and a lack of social support in their communities. For example, the youth described individuals with HIV as singled out, taunted, and avoided.

Stereotypes and discrimination are the most frequent views attached to HIV. Despite medical advancements for treating the disease, adult program personnel and youth said it is still considered a death sentence in their community. While many of the respondents described having HIV with negative terms such as leading to hopelessness, the views of the disease as preventative and a second chance at life were discussed nearly equally. For example, the adults described a second chance for youth to gain determination, health awareness, and empowerment to live with

HIV, while the youth described a second chance for reinvention, health awareness, and educational opportunity.

The main client suggestion to addressing HIV is client awareness due in part to education in schools, media campaigns, and outreach efforts. However, adults expressed concern about youth taking preventative action based on this awareness (e.g., "There's this disconnect between them knowing it and then actually doing it"), and youth cautioned against stereotypes when specific groups are depicted with the disease. Adult program personnel and youth clients provided suggestions for enhancing client receptivity, including who, how, when, and where HIV education messages are delivered. For example, youth frequently discussed using peer education by similar age youth to increase youth receptivity to HIV education (e.g., "You ain't gonna talk about it with no grown man or grown woman about it, for real. You gonna talk to somebody around your age").

### **Comparative Analyses**

Two comparative analyses allow for an elucidation of the role of Human Immunodeficiency Virus (HIV) stigma in program implementation. The first is an analysis of responses provided by adult program personnel by program type. Comparing HIV service program personnel perspectives to those of at-risk programs provides an understanding of the role of HIV stigma in program implementation. The second is an analysis of youth responses by program type. Comparing client perspectives among HIV service programs to those of at-risk programs provides an understanding of personal and social influences on the accuracy of program efforts to address HIV stigma. Archival materials from these

programs are discussed as supplemental information for the interviews and group interviews. The following analyses are organized according to the research questions.

**Research question one.** *Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

**Adult program personnel responses.** The responses from the four interviews with adult program personnel from programs that provide HIV services yielded similar responses to the four interviews with adult program personnel from programs that provide at-risk services.

*HIV service program responses.* Among the adults from HIV service programs who confirmed youth with HIV are stigmatized, each provided statements about the ways youth are avoided, separated, or feared. Describing an "othering" of the disease, a respondent said, "The disease amplifies problems that already exist...it sort of just amplifies marginalization...like us, we don't have it, but *those* groups might have it." Another adult said, "If you're a young, gay male or young, Black male, the idea is that if you have HIV then you got it because you're gay even if it was from IV drug use or heterosexual contact." Moral judgment attached to HIV is reflected by a respondent who said, "It's like if they have HIV, they're dirty. . .they did something wrong."

Statements about positive aspects of having HIV were minimally discussed within two interviews. For example, a respondent said it raises awareness about other social problems such as poverty. The other respondent said a diagnosis with

the disease stopped "individual clients who themselves were out of control and were binging on drugs and sex. But usually that's when they're through recovery and once they've accepted and they're on the other end."

Adults discussed several reasons for why youth with HIV are stigmatized differently by race, gender, and sexual orientation. For example, a respondent said, "With Black and White in this neighborhood or this area, they seem to think that when you are Black and you have the virus, because there's so many of us in this community that may have it, that it's overlooked. Like it's almost like people aren't caring about you, they're not reaching out to you as they would do in the White community is kinda what I'm getting from the kids that I work with." In comparison, another respondent said, "The stigma in the African American community, between others in the African American community, the idea that it's spread by men on the down-low instead of also being spread by heterosexual couples, and the uh, the African American men in prison." Down-low is a term that means identifying as heterosexual while engaging in homosexual activities (Ford, Whetten, Hall, Kaufman, & Thrasher, 2007; Millett, Malebranche, Mason, & Spikes, 2005).

The majority of participants described a prevalent conceptualization of HIV attached to specific characteristics. "If you're straight and you have it," said a respondent from an HIV service program, "people automatically think you slept with somebody on the down-low." Another respondent said, "When women are thought to be infected, more times what comes up is, 'Oh, her boyfriend must have been sleeping with other men' or 'She must have been sleeping with people for

money, she's a sex-worker' cuz it's typically still linked to gay youth and prostitutes."

*At-risk service program responses.* Among the adults from at-risk programs who confirmed youth with HIV are stigmatized, each provided statements about the ways youth are avoided, separated, or feared. A participant said, "In this community, they seem to be more accepting when you're gay and you have it because people already think that it's the gay man's disease, that people have it because they're gay like it's expected or something." Another participant said, "I think there's more discrimination between not so much boy or girl or their race, but more about their homosexuality. So if you happen to be gay or lesbian or transgender, you're automatically...you're already tuned into thinking, 'Oh this person's probably got AIDS.' Forget the HIV part."

Positive aspects of having HIV were rejected within all of the at-risk interviews. For example, one respondent said, "They're treated like this monster." However, two respondents described indirect gains including social and scientific progress related to the disease.

When asked if youth who have HIV are stigmatized differently by race, ethnicity, gender, or sexual orientation, the majority of respondents described how Whites, gay men, men on the down-low, and female prostitutes are seen as primarily responsible for the disease. For example, a respondent said, "The thing about race is, a lot of times if a White male turns up positive, it's 'Oh ok, he's positive, he's gonna get good treatment,' but it's almost like if a Black person is positive, a Black gay man

is positive, it's like, 'Ok, well he's just waiting to die.' It's like it's not expected for them to be at the same level, the same playing field when they turn up positive."

Over half of the respondents said girls and young women are subjected to a double standard. For example, a participant said, "With the women who have it, they're automatically stigmatized as this whore, because. . .if a man has it, 'Oh, he just slipped up. He just, you know, slipped up and didn't use that condom that one time."

All of the respondents serving Latino youth said Latinos stigmatize and perceive the disease differently. Describing the need for multiple approaches to addressing HIV, a participant from an at-risk program said, "People bring their countries with them, so whatever preconception they have from their countries they will bring with them. Most of the things that are around is that it's a death sentence, you know, because in their countries medicines are not readily available, support is not readily available, conversations about sexuality are not as open as they are here (even though here we think we're still closed)...you know, they lower the voice [to whisper] 'It's *AIDS*.'"

When asked what happens to youth when it is known that they have HIV, the respondents most often described blame and avoidance on the part of those who do not have HIV and isolation on the part of those who have HIV. One respondent said, "They withdraw. They don't want to tell anyone, so they become loners [or] may run away." This statement suggests that social distance is both a process and outcome of HIV stigma.

***Youth client responses.*** The language youth use to refer to HIV is different from the language adults use to refer to HIV. The African American/Black youth in particular use the following terms: burnin' or mixin' (referring to multiple sexually transmitted infections, including HIV), **A. I. Die. Slow**, AIDS is low, the package, the clap, the bug, the shit, the juice, the sauce, the stuff, the flow, the flu, the foolishness, the monkey ("on yo back"), the gorilla, the kitty, the 30-day notice ("before you expire"), fall-out-find-out ("fall out when you find out"), the gay disease, house of pain, the death, the deadly killer, the Hurricane Katrina of DC (i.e., a catastrophe afflicting African Americans), **High five** (i.e., a raised hand signal that spells H.I.V.) and the virus. Many of these terms reflect negative perceptions of the disease and misconceptions about HIV transmission. For example, one respondent provided the following explanation: "A lot of folks think that in order to get the disease you need to be the receiver. Meaning that for guys, if you're being penetrated you're the one who will be receiving the gift. That's why they call it the package or the gift. They don't really see it as it being reciprocal. They see it as giving it out. As something that needs to be discharged...packaged...to receive."

Latino youth said they use more direct terms in their community by saying "positive." These youth also said the disease is joked about among Latinos; "When you're talking with some friends, you'll say he has *el perrito* [a little dog]."

***HIV service program responses.*** Among the youth from HIV service programs who confirmed youth with HIV are stigmatized, each provided statements about the ways youth are avoided, separated, or feared. For example, a youth said, "Some people will post it on Facebook, 'Watch out for this person' or you know say stuff

like that. That will ruin your life cuz you're like, 'What am I gonna do?' People see you and will be like...people just get grossed out." The following statements are emblematic of the avoidance and peer gossip attached to youth with HIV: (1)

"Friends that you had before, they find out that you have HIV, they go away gradually cuz they only associate with you based on what other people think;" and (2) "When people find out you have HIV, or if they find out you have an STD or something, people talk about you behind your back."

Statements about positive aspects of having HIV were minimally raised within three group interviews. For example, a participant said having the disease is a "lesson learned." Another respondent said, "Some of 'em get determined and motivated to do better and live a better life."

Youth discussed several reasons for why youth with HIV are stigmatized differently by race, gender, and sexual orientation. Most discussed misinformation and assumptions about how youth were infected. For example, a youth said, "I think a lot of times, I guess if a gay person has HIV, they'll say somethin' like, 'Oh you deserved it' or 'You already have it' rather than, like a straight person gets it: 'Oh, something coulda' went wrong' or somethin' like that."

*At-risk service program responses.* Youth from at-risk programs provided different reasons for stigma compared to those from HIV service programs. For example, a youth expressed the stigma he felt by saying, "After this person got it, I ain't sayin' particulars, we used to be hangin' and all that. Now, I don't want to be nice to him cuz that creep me out. I had nightmares, I ain't been able to sleep!" When asked why it creeps him out, he said, "I'm afraid of it...like if your friend a crack-



head, it's gonna change the way you see him. Like if your friend a faggot, it's gonna change the way you see him." Another respondent described the following scenario she witnessed at her school: "The kids didn't want to drink at the water fountain with her. They just refused to drink at the water fountain, like, 'I don't wanna get AIDS from the water fountain,' like, 'I'm scared I might catch it.'"

Participants within all interviews discussed myths attached to race, gender, or sexual orientation. A youth participant said, "They make up different stories for other races...I think they say someone is goin' around if they're African American or a Hispanic, those are generally more...like people go to sleeping with someone or you don't care." Describing how girls and young women with HIV are viewed, a participant said, "Oh she's a roller, like that kinda stuff. She doin' it to everybody, she get around...like a prostitute."

Participants also provided rich examples of how these differences manifest. For example, a respondent said, "Whites get embraced. Like, 'You gonna be fine. You gonna be ok man, it's ok, we can still hang out.' African Americans never live it down." Another respondent from a different at-risk program said, "I do think it's different between gender. . .if a boy gets it from a girl, it'd be easy to say she was rollin'. . .she been havin' sex with everybody else. She gave it to me. They both got the disease in the end, but it's like, 'Ok, yeah she rollin,' even if a boy gave it to a girl." In addition to race and gender, a respondent discussed the following in relation to HIV stigma and sexual orientation: "Well gays already get treated differently. So if you gay *and* you got AIDS, psht, you get one more you struck out. One more...three strikes you out."

Positive aspects of youth having HIV were raised less frequently among participants from at-risk programs than HIV service programs. Youth within one group said it is good to know about youth with HIV since it makes them aware of the need to use condoms, and youth within the other three groups said there is nothing positive at all about having HIV.

Youth were asked how people with HIV are identified, particularly with respect to what someone with HIV most commonly looks like. In half of the groups, youth said they can tell someone has HIV by looking at them. For example, participants described people with HIV as "losin' weight," "skinny," and "frail." One respondent said, "They [youth without HIV] only know if they [youth with HIV] tell you. Or if they got bumps or something like that."

When asked what happens to youth when it is known that they have HIV, the majority of respondents expressed a negative view of what it would be like to live with the disease. For example, a respondent said, "They feel like they can't do anything. Your world will have ended. They're self-conscious." Youth within half of the groups reached consensus that suicide is a likely option. For example, a youth would say he or she would kill him or herself, and then other youth would agree by saying "yeah" or nodding in unison. It is notable that suicidal ideation attached to a potential or actual HIV diagnosis is a common reaction according to the professional and research literature, in addition to the experience of this researcher (Cooperman & Simoni, 2005; Gielen, McDonnell, O'Campo, & Burke, 2005; Shelton, Atkinson, Risser, McCurdy, Useche, & Padgett, 2006).

**Archival materials.** Six pamphlets and two HIV screening forms provided by program personnel illustrate educational tools used to address HIV stigma. All of the programs that use pamphlets receive them from ETR Associates or similar national health materials clearinghouses based in California. The year of publication for these materials ranges from 1987 to 2010, and the average age is eight years old (2002). All but one of the pamphlets and screening tools have the word HIV written in large (14 to 16 font) letters on their front side, and over half depict teenagers in clinic or school settings.

The messaging format within all materials is inquiry (e.g., "Did you know?"), and all of the pamphlets use directive (e.g., "Don't share needles," "Don't have sex if you feel out of control") and informative statements. The majority of risk factor and transmission mode messages are warnings against injection drug use/sharing needles and unprotected sexual contact/intercourse. Additional messages include tattooing, bodily fluids, rape, and blood transfusion. One also mentions perinatal (mother-to-child) infection, and one mentions the risk to healthcare workers by needle stick. The majority of prevention messages are HIV testing and condoms/barrier protection, followed by avoiding unprotected sex, abstinence, avoiding drug use, avoiding alcohol, and practicing relationship fidelity.

**Summary.** All of the respondents confirmed HIV stigma affects how youth with HIV are perceived and treated differently. Program personnel from the HIV service programs and at-risk programs are particularly aware of how race, gender, and sexual orientation stereotypes intertwine with common assumptions about the types of people who are most infected. Youth from HIV service programs expressed

positive aspects about the disease more often than youth from at-risk programs, and the misunderstanding among several youth from the at-risk programs who experienced stigma, expressed stereotypes and myths, and said they can identify people with HIV by what they look like are especially concerning. While clearly indicated HIV archival materials are present within all of the programs and contain messages about the most common HIV risk factors and transmission modes (injection drug use and unprotected sex), they are outdated and not locally created.

***Research question two.*** *How do individual program components (goals, objectives, and activities) address HIV-status stigma?*

***Adult program personnel responses.***

*HIV service program responses.* The adults from HIV service programs described multiple approaches to address HIV-status stigma. All programs provide condoms and HIV testing, and two adults said their availability is testament to the ability to discuss sex and HIV concerns. Two programs incorporate stigma reduction into their curricula, and a clinic-based program works to address HIV stigma as part of clinical care. For example, a respondent provided the following rationale for addressing stigma to improve medication adherence: "Stigma is really strongly associated with taking your medications, and you know, that's a big barrier. You know like pill fatigue and looking at your medicine makes you remember that you have the disease."

When asked if there are institutional limits on the ability of program personnel to address HIV stigma, all of the respondents said there are none. Facilitators include openness to discuss sexuality, having HIV positive personnel

who are open about their status, and facilitating peer education for youth to know their age group is affected.

The use of proscribed curricula was cited as an additional limitation, mainly due to unreimbursed time to deliver educational content. For example, a respondent said, "It is a strict curriculum that we follow, that we're paid to do, but anything else, we do that just because." This response illustrates how strict curricula and curricular monetization can hinder HIV education that program personnel may recognize the need to deliver.

*At-risk service program responses.* Program personnel from at-risk programs describe differing capacities to address HIV stigma. All of the respondents said they knew of at least one youth in their program who was HIV positive, and half said their program specifically addresses HIV stigma. Among those who did not address HIV stigma, one said program personnel stigmatize HIV, and one said the issue has not been encountered. However, all respondents previously said they knew about stigma, myths, and misinformation attached to youth living with HIV.

When asked if there are institutional limits on the ability of program personnel to address HIV stigma, half of the respondents said there are none. One participant said confidentiality policies hinder linking youth to other programs, and one participant said established institutional beliefs expressly prohibit discussions about contraceptives (barrier protection). For example, a respondent described how confidentiality can be a barrier to linking youth to services by saying, "I can't go above and beyond getting in contact with this kid, or I have to go through loopholes to get them insurance outside of their parents' insurance that they already

have...and maybe I need this person [a referral agency representative] to actually realize this person [the youth] needs help, but I can't tell them their name." A respondent from an abstinence-focused program said, "If someone comes in and says, 'I think I might have HIV. I'm not sure what I can do,' the only thing we can do is refer them back, you know, to the doctor's and then just tell them, 'Hey, don't engage in any sexual activities any more.'"

Cultural competency and ongoing, open conversations about sexuality and stigma were said to enhance the ability of program personnel to address HIV stigma. For example, a respondent said, "We started seeing a lot of African diaspora participants, and they don't have the same views as the Latino community that we were serving. When they bring their countries with them, it's a different type of stigma they bring in." Recognition and valuation of cultural variations are important foundations for moving beyond cultural blindness toward more advanced stages of a cultural competence continuum (Hanson, 1998; Hernandez, Isaacs, Nesman, & Burns, 1998).

The use of proscribed curricula was cited as an additional limitation, mainly due to the incorporation of HIV into broader topics. For example, a respondent said, "A lot of the groups that we train only want us to come for a couple hours at a time, so trying to get the whole spectrum of sex education and then having to do a whole lesson on HIV and stigma is like, yeah [sigh of frustration]." This response illustrates how strict curricula and topic de-prioritization can hinder HIV education; because of time limitations to deliver a specific amount of content, HIV stigma information is omitted.

Additional constraints include peer norms among youth that prevent communication about HIV. All of the adults cited the sense of invincibility among at-risk youth and peer expectations of sex. For example, a respondent said, "Especially with guys it's even harder, because with them it's just the thing to do to sleep around. Like you're supposed to get all these girls, and if you've been having unprotected sex, so what? If you don't have an STD, as long as she's on birth control then you're ok." Another respondent provided an example of a 13 year old who is "very promiscuous. So every day [program personnel are] having conversations with her about not just getting pregnant, but contracting HIV and STDs and her responsibility, and she's like, 'Oh, that's not gonna happen to me! It's alright, you know.'"

***Youth client responses.***

*HIV service program responses.* All of the youth said HIV is talked about in their programs "daily" or "all the time." When asked what would make it easier for an adult from a program to educate youth about HIV, youth within two groups said peer education from HIV positive youth advocates since youth are more receptive to someone closer to their age.

Youth within two additional groups said social rather than written media would be better for connecting with youth. For example, one participant said, "Most of the kids, if they get pamphlets with condoms in them, then they just throw away the pamphlets. They [educators] need to do those videos on Facebook and Twitter. If they [youth] see somebody their age, then maybe they'll change." This statement raises considerations about adult versus youth appropriateness regarding visual

condom demonstration and minors' access to this information (e.g., Project T.R.U.S.T., 2010).

Youth within all groups said written and visual materials can create a better environment to educate about HIV, though format, content, and context influence their effectiveness. For example, a participant said, "If you're saying, 'Protect yourself, use a condom,' *why* should I protect myself? *Why* should I use a condom? Give specific information. Be very clear instead of listing symptoms and a lot of information."

Commensurate with HIV messaging through media, youth discussed how to better present educational content. Youth suggested a direct approach reflecting their language. A youth from an HIV service program said, "Don't sugar-coat it, cuz if you sugar-coat it then they [youth] aren't going to take it serious. Don't be like, 'Just use condoms,' tell 'em exactly what to do. Be straightforward and they'll take it serious." Another respondent said, "What you should do is speak youth language, cuz a lot of them say, are created by adults, and have a focus group with the demographic you're trying to reach cuz there's a lot of adultism, feeling that youth, our words, are not valuable."

*At-risk service program responses.* All of the youth from at-risk programs said HIV is talked about in their programs, and half said it is discussed indirectly as part of a lesson on sexually transmitted infections or healthy relationships. These youth said that testimonials from advocates who are living with HIV would make this easier to educate youth about the disease, since youth would be more receptive. In addition, all groups discussed how written and visual materials can create a better



environment to educate about HIV and emphasized the importance of youth participation. For example, a respondent said when adults provide HIV education, they need to "stop lecturing" and "have the young people participate rather than just telling them [by] asking their opinion, including them."

In addition to youth participation, youth discussed the effectiveness of incorporating testimonials from advocates who are living with HIV. A youth from an at-risk program said, "In my 9th grade year, it was a group of people who came in to talk about the HIV virus, like this lady come in and said, 'Oh I've got it cuz I was shootin' up' and all this other stuff. I think that's when it really became real to me when she came in and was talkin' about it. I was lookin' like, 'Dang, this is serious!'" Another youth from a different program said, "A homosexual guy came into my school, he had AIDS he told us. I guess he had no problem tellin' us. And he talked to us...I guess that was the first time I really *thought* about it, thought about it. But he came in and he told us he was homosexual and he had HIV...it made sense cuz this was actually a person who experienced it and not just a video."

Commensurate with who delivers HIV education, all of the youth discussed how to better present educational content. Describing the pamphlets used by her program, a participant said, "I guess like maybe they were geared toward like inner-city youth or something. So it was all this trying to be hip, like trying to be cool language. And there's this graffiti on it...it just sets up this stereotype that like kids of color, like people who live in urban areas are the ones who have this, because you have to have this special type of language for these kids...I don't know it just seemed kinda like racist." This statement suggests that adult educators using youth slang

may want to pilot test their messages for youth-determined appropriateness and receptivity.

**Archival materials.** Six pamphlets and two HIV screening forms provided by program personnel illustrate several limitations among the educational tools used to address HIV stigma. First, most materials were displayed within shelving (e.g., pamphlet racks) and were co-located with other health-related materials. Second, less than half of the materials address incorrect assumptions and myths about HIV/AIDS, including transmission by mosquitoes, casual contact, public surfaces (telephones, toilet seats), donating blood, sharing food or drink, and tears, saliva, sweat, and urine. Finally, among those that did address assumptions and myths, the at-risk program materials do not focus on the incorrect belief that transmission occurrence can occur through casual contact (e.g., touching, shaking hands) and public surfaces. Despite these limitations, messages about risk factors/transmission modes and prevention methods were nearly equal by program type. For example, HIV service program and at-risk materials both cover bodily fluids and injection drug use.

**Summary.** All of the respondents described how programs are addressing HIV-status stigma in response to various institutional and curricular constraints. While HIV program personnel cited fewer constraints to deliver educational content than the at-risk program personnel, the time to deliver instructional material beyond the proscribed curricula is largely unreimbursed. Since at-risk personnel do not focus solely on HIV, the inclusion of HIV stigma into broader topics is a similar challenge. Youth responses from both types of programs illustrate the importance of

youth involvement in HIV education, whether as peer mentors or content reviewers. According to the youth, the archival materials do not provide comprehensive information and were even offensive (i.e., characterized as racist) in one instance.

***Research question three.*** *How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?* Since there is no explicit structure for systematic HIV stigma reduction efforts, findings reflect potential educational areas to enhance. The following section also illustrates the difficulty of service individualization based on HIV sero-positive disclosure and risk assessment questionnaires. Program tailoring based on other available data such as local surveillance reports and community input follows an informal process to address HIV overall, let alone HIV stigma.

***Adult program personnel responses.***

*HIV service program responses.* Normalization is a term used by all HIV program personnel to describe how they informally address HIV stigma. The youth they serve interact with HIV positive staff who are frequently open about their status, condoms are displayed openly, and all respondents said they have open conversations about HIV. For example, a respondent said, "Being that this is an agency that is an HIV prevention, HIV care, et cetera agency, it's something that we see and deal with every day. So it kinda, you know, once again nothing curriculum based, nothing direct, but just our experience sitting and having conversations with people all day makes us kinda...makes it a little bit easier when you try to have conversations to help out the youth."

Despite all of the program personnel citing how HIV stigma is a problem for the youth clients they serve, none of the programs have a lesson plan specifically focusing on HIV stigma or collect data about HIV stigma through formal evaluation methods. HIV stigma is a hidden curriculum, discussed at the margins of approved, official educational content (Apple, 1971). One respondent said, "It is a strict curriculum that we follow, that we're paid to do, but anything else, we do that just because." By making HIV a normal topic of conversation, program personnel are reducing the perceptual distance between clients and their relationship with the disease, which is an indirect way to reduce HIV stigma.

Clients travel far from where they live to receive HIV services due to HIV stigma, which makes capacity planning difficult. For example, a respondent said, "Because of where we're located, there are a lot of people from Virginia and Maryland who we're not able to see. Our case managers are unable to see them because we're not funded to see them. You have to actually be a DC resident." Clients are also dropped off down the street or walk around the block before entering HIV service programs due to the stigma of being seen.

HIV disclosure to one's social circle is a key ingredient to program individualization for minors in particular, because parents need to authorize or at least be aware of certain program activities. For example, a respondent said, "I had a guy who was 16 and sneaking into our programs. I didn't know until his mother was following me here one day. And she was like, 'Well what's going on here?' and I was like, 'You didn't know your son was coming here?' ...so he wanted to come out and get information, but didn't want to tell his mother, and his mother was like, 'Well

yeah, all he had to do was *tell* me where he was going instead of disappearing every night!" Another participant explained how disclosure avoidance negatively affects treatment engagement with the following: "There was one person we wanted to get back into care who was very young, who dropped off the face of the planet and didn't make any of his appointments, his number didn't work. I wanted to go to his house to talk with him and bring him back in, but he was living with his grandmother and hadn't disclosed [to her]. It was very difficult. We were at sort of an impasse there." This example illustrates the difficulty of program individualization in a community setting or personal situation that prevents HIV identification.

Respondents described how HIV disclosure to family members is more difficult in comparison to friends and intimate partners due to a lack of control over whether HIV status information is shared. Respondents provided the following examples of difficulties: (1) "Like for example, those people who...may want to tell their parents, but they may not want to tell their sister. Even though they're the same close proximity, for some reason they pinpoint certain people to tell. Then there's this gap between them and someone else;" and (2) "When you're talking family, you're talking generations and your full relatives, so fear of telling your mom that you're living with. And all of your extended relatives in North Carolina are going to know. So you kind of lose control over that."

In comparison to controlling disclosure among family, fear of the spread of this information among friends and intimate partners was raised as an additional concern. A respondent from an HIV service program said, "Most of our youth have

the hardest time disclosing to the other youth who come to the youth center just because of that fear of rejection...there's still that level of fear, and that could definitely be stigma related." Another respondent said, "Friends and intimate partners is the hardest part for them, cuz that's the big fear, it getting out into the community and everybody knowing. And you know, especially when you're young you can be best friends with someone this week and in two weeks they're your enemy, so what's gonna happen with the information that you gave them? Are they gonna go and blast it all over Facebook?"

Given the difficulties of tailoring program components to the individual needs of HIV positive youth clients within disclosure-avoidant situations (due to stigma or other concerns such as safety), other available sources of data were said to influence the way programs address HIV overall. Nearly all of the respondents expressed an awareness of needs assessment data from statistical reports on the youth populations they serve (e.g., CDC, DC Department of Health) and articulated how these and other data (e.g., community surveys, service utilization data, and formal program evaluation data) specify the number and type of clients served by their programs. For example, a respondent said, "We recently I believe got a grant to do outreach at the [name redacted], which is a sex club. I think that was directly related, seeing like from an epidemiological way the idea to stop HIV is to stop the way people are getting infected from infecting others."

Additional input from their local communities was said to be largely informal through community networking (e.g., coalitions or events such as AIDS Walk Washington) or a concern primarily among their program administrators. Examples

include two respondents who said, "We do have a community advisory group; I think that helps inform the Board of Directors" and "Yes, I don't know to what capacity, because I'm not 'up there' yet."

*At-risk service program responses.* At-risk programs do not address HIV stigma through normalization of HIV as a frequent topic of discussion. Nearly all of the program personnel expressed a general awareness of the high HIV infection rate in Washington, D.C. and the transmission risks among on the youth populations they serve, though how this awareness influences program components is unclear. For example, a respondent said, "I think it's more-so a personal thing. I don't think we as a program follow the statistics. I think we could do a better job with that piece. I know the statistics because I try to keep a grasp of what's going on. But if you're not a person who's really trying to fight the fight, or trying to be in the know, you probably won't." Additional input about HIV from their local communities was said to be largely informal through community networking (e.g., youth or health-focused coalitions).

Similar to the findings from the HIV program personnel, all of the at-risk program personnel cite how HIV stigma is a problem for the youth clients they serve. However, no lessons plans or evaluation methods focus on HIV stigma. Within these programs, the topic of HIV overall can be lost when individual staff deprioritize it by cutting it from lessons on health or blending it into lessons on sexually transmitted infections. Program personnel may even need to first address their own stigma before providing education to youth clients to reduce HIV stigma. For example, a respondent described a sequence of events during a professional

training on client confidentiality where a colleague asked, 'If a youth comes in and says, 'Hey I have HIV or AIDS or what-not,' then what do we do with that information? Should the whole organization know about it?' "The [trainer's] response to that was, 'no.' And then some of the [program personnel] responses were: "Well no! I don't think that's right! I need to know who's infected with HIV!" There was just a lot of anger going on in the room because they felt like, 'If someone is infected with HIV, I *need* to know so I know who I'm working with and how to protect myself.'" This example illustrates how client disclosure can potentially result in negative responses within programs ostensibly designed to meet client needs.

Half of the at-risk programs identify youth who have HIV through risk assessment intake questionnaires. However, youth were said to not respond to this question or provide an inaccurate response. Citing knowledge of more HIV positive youth in her program than are reflected by internal data, one participant said, "I would say about 85% of them lie on the application...let me tell you, and I don't know if the process changed now, but I know when I first started working here [2 years prior], that's not the kind of thing a kid wants to sit there [and share] with you. 'I came here, I'm in a crisis, and on the first day I don't even know you for five seconds and you're already asking me if I have AIDS?' You really need to build a trusting relationship with this youth where they feel comfortable." This statement is corroborated by a youth statement regarding discomfort when talking about HIV with unfamiliar adults.

The link between disclosure to family, friends, and intimate partners and the need for program services is suggested by the following: "This young lady...I think



she had a hard time sharing with her family about her having HIV because she of course didn't know what the response was going to be, like in terms of 'Ok you know what? I don't need you in my house!' I think a part of it had to do with her reason for of being here in our homeless shelter." Despite the HIV catalyst in this situation, this program is not set up to individualize services to address HIV-related needs or HIV-related stigma.

Diverse priority groups cited by program personnel as most at-risk for HIV include ages 11 to 17, 15 to 19, and 19 to 25. A participant provided the following rationale for why the 19 to 25 age group is most at risk: "They're at an age when they think they know everything...that's during the time when they're just starting to drink and smoke and experience things, so I find that age group—a lot."

***Youth client responses.***

*HIV service program responses.* Youth in all group interviews corroborated the program personnel statements about being able to talk about HIV informally. The following provides an example of the value youth place on open access to HIV services and discussing the disease: "They should have more schools. Like more organizations like this in schools. Where they [referring to youth] can just go into the office and talk what's on their mind and get tested. Most people don't just come to centers to hear about HIV and AIDS."

While all groups provided examples of HIV stigma posing problems for youth, none discussed specific program components that are addressing HIV stigma. This suggests that the normalization strategy among these programs is either

working or youth are more acutely aware of HIV stigma operating outside of these programs.

In contrast to the program personnel who discussed disclosure-avoidant situations and the difficulty of providing HIV related services, nearly all of the youth participants said youth would have concerns about disclosing they have HIV to family, friends, and intimate partners. However, participants said it largely depends on the decisions of others to provide support or reject youth.

When youth were asked if there is a priority group of youth that is most at-risk for HIV, the youth said alcoholics, the uneducated, under age 25, prostitutes, drug addicts, and ages 14 to 21. Youth within all groups said there are stereotypes of youth with HIV and discussed the influence of mass media depicting specific groups. Discussing people of color in HIV advertisements, a youth said, "I think when someone is lookin' at that and they mostly heard only the stereotypes of Black people only get it or people of color that they mostly see, then that's just confirming that belief." Another youth in a different group said, "It causes people to have stereotypes. I think they need to show, cuz it's a lot of different races that have it, that's been infected with HIV/AIDS, but they don't really speak too much on it."

*At-risk service program responses.* Although HIV stigma may be the primary factor leading to the need for program services, HIV is marginal to what these programs are designed to address. As a result, HIV infection and HIV stigma among target clients served by these programs may be increasing, but indicators are not in place to identify trends and subsequently shape the way the program provides services. For example, an abstinence-only teen pregnancy program includes HIV

avoidance but does not shape its educational programming around disease prevention for HIV positive youth or informally known sexual behaviors (lack of condom use) among at-risk youth.

Responses from the youth participants reflect an awareness of several program blind spots. For example, the need for condom education was raised within the group interview at the abstinence focused program. Youth within the other group interviews discussed a need for new, updated education about HIV to move beyond hearing the same information "over and over." A sense of missing information is apparent in the statement, "If an adult is talking to me, then I want them to tell me *everything*. Keep it real, like I don't like people sugar-coating stuff cuz I'm just used to people telling me."

Disclosure of one's HIV status and risks for acquiring the disease are different in at-risk programs compared to HIV service programs since at-risk programs rely on trust and comfort between adult program personnel and youth clients. Individual efforts by program personnel or self-determination to disclose by youth clients are situation-dependent rather than a standard (e.g., policy supported) course of action. Considering staff turn-over and client migration into and out of these programs, identification of the target client's HIV related health needs (let alone HIV stigma reduction needs) can be hit or miss.

Without asking about their personal concerns about HIV disclosure, youth were asked if youth in general would have concerns about disclosing they have HIV. While nearly all of the youth participants confirmed youth would have significant

concerns about disclosing they have HIV, the majority of responses focused on disclosure outside of the programs.

Among those who said it would be difficult to disclose to family, friends, and intimate partners, the most common concern expressed by the youth was disclosure to friends. For example, a participant said, "You afraid they're gonna look at you a certain way. Like everything about you is gonna change like, 'She don't know me anymore.'" However, one participant provided the following counter-example: "I wouldn't care, I'd tell people. Most likely a female ain't gonna tell a dude. If a boy gets it, he'll be braggin' that he got with all these girls."

Youth also discussed priority groups that are at most at-risk for HIV. Responses included people who are "low class," everyone that does not have HIV, youth who "think they're invincible and can do whatever," and those who are gay. One participant said, "The gay people, they more likely to catch it than the straight people."

Youth in all groups said stereotypes are attached to the common characteristics of youth with HIV and discussed the influence of mass media depicting specific groups. The majority of the groups discussed seeing media depicting African Americans or Blacks with HIV most often, and the remaining groups discussed seeing diverse media (different races, interracial gay couples). Half of those that said African Americans or Blacks were seen most said these depictions accurately reflect infection statistics and raise awareness, while the other half cautioned against group-specific depictions of the disease (e.g., "They should focus on everybody, cuz everybody is gettin' infected by it").

**Archival materials.** No archival materials provided by personnel address HIV stigma. Instead, these materials address the topic of HIV overall. The materials provided by program personnel illustrate several disconnects between their depictions and target clients' characteristics. While half of the pamphlets depict multiple races and ethnicities, two depict only African Americans and one depicts only a White teenager. Among all of the materials, only one third depicts or mentions girls or young women. No transgender youth are depicted or mentioned, and sexual orientation is mentioned only within the HIV/AIDS risk assessment forms. One material further removes the association between the youth depicted and having HIV by stating, "The people in this brochure are models. The models have no relation to the story or issue presented."

**Summary.** Participant responses and observations during data collection provide context for how HIV service programs and at-risk programs operate differently. HIV service programs are known to provide HIV testing, have more condoms available near their front doors with large, inviting signs (e.g., "Take what you need!"), and have many program personnel who are open about being HIV positive or have friends, family, or intimate partners who have HIV. At-risk programs rely on trust and comfort to talk openly about HIV with their youth clients, do not typically provide enthusiastic encouragement to use condoms, and do not have nearly as many program personnel living with HIV. These differences partially explain how HIV overall is not a day-to-day special consideration for educating youth in these programs.

Given these differences, lack of disclosure was found to have an influence on HIV education within both program types. Responses indicate that the identification of the target client via disclosure relates to the ability to reach youth to deliver services, accurately assess groups who are most at-risk, and prioritize program components to address individual needs related to HIV, let alone HIV stigma.

Nearly all respondents discussed how disclosure is a consistent concern due to unknown reactions among friends, family members, or intimate partners, the spread of information about one's HIV status without permission, or rejection. HIV service program personnel described how a lack of HIV identification impedes linking youth to services. Youth within the HIV service program group interviews provided nuanced considerations about disclosure by hinging concerns on the situations youth encounter.

Inaccurate identification of the target client based on assumptions rather than data can also lead to mismatches between program components and priority groups who are most at-risk for HIV. None of the individual interviews provided redundancy, and none of the group interviews reached consensus regarding priority groups who are most at-risk for HIV. However, critiques of how the media depicts common characteristics of youth with HIV were provided by youth from the HIV and at-risk programs. The youth in both program types expressed an awareness of their race and HIV within media, and youth from HIV service programs in particular described how targeted messaging can lead to stereotypes. Since many of the archival materials are not reflective of the populations the programs serve by race, gender, and sexual orientation, a target client mismatch is evident.

**Research question four.** *How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?* Since stigma reduction efforts are informal and all of the programs lack systematic program evaluation focusing on HIV stigma, the following section provides responses regarding the ability for clients to provide feedback on whether program services meet their educational needs related to HIV overall, youth receptivity to HIV education, and the effectiveness of HIV education.

***Adult program personnel responses.***

*HIV service program responses.* All of the program personnel from HIV service programs said they use formal and informal evaluations or surveys to gain feedback from their youth clients. While informal, ad-hoc discussions are ongoing, program personnel use formal evaluations at varying times among programs (i.e., after each training or intervention, annual satisfaction surveys, periodic debriefings). For example, a respondent said, "Mostly it will be like if [receptionist name] will get letters from clients with complaints or things they say they liked about the clinic, that's kinda how we get our feedback. Sometimes they'll tell us directly, you know, like 'That was helpful' or 'That really helped me.'"

One participant articulated how client feedback was used to improve the program. "They mentioned we give a lot of hand-outs, so we ordered flash drives." Program staff subsequently discovered the flash drives made it easier for the youth to review and find the information. "Maybe they get in a debate with some of their friends about something and they don't have that paper, then they have it right on the flash drive and they can pull it up. It's an official document to back, you know,

your story." Youth corroborated the utility of having enduring HIV education materials on flash drives and websites.

Half of the respondents said youth are generally receptive to HIV education, and half said it depends on their developmental stage of change (referring to a model by Prochaska and DiClemente, 1992) or their engagement with a peer educator. For example, a participant said, "I've worked with youth in numerous groups [saying] 'You've been there, you know these things, but for some reason you're still getting pregnant three times in a row, you're still coming to me talking about STDs' ...so they listen to me and they hear it, but they're just not *acting* on it."

When adults were asked what they found to be most effective for educating youth, diverse responses included making lessons interactive and fun, establishing trust, breaking down medical terms into plain language, and establishing peer leaders. All of the respondents said having open communication about sexuality is most effective for educating youth about HIV. Additional statements included having culturally competent program personnel and breaking down HIV terms into plain English for youth to "re-verbalize what it means."

*At-risk service program responses.*

All of the program personnel from at-risk service programs said they gain mostly positive, informal feedback from their youth clients. They also gain formal feedback from youth to evaluate different service aspects among these programs. For example, two programs ask youth to evaluate the staff, one asks youth to evaluate specific program activities, and one asks the youth to evaluate the overall program.



All of the respondents said youth are generally receptive to HIV education as evidenced by their informal, ad hoc discussions. Respondents also said the youths' perceptions of how their programs provide services differ by education and experience. For example, respondents said schools approach the topic of HIV at different grades. A participant from an at-risk program that predominantly serves older (ages 18+) youth said, "The older set tend to take it [program services] more seriously than the younger set...24, 25, a lot of them are already raising a child. They know what it's like to try and fend for a family as opposed to an 18, 19 year old who's still living at home with mom [and] really don't have a clue to know what it's like to have to pay bills, to be on your own, to not have a net, you know."

When asked whether they measure changes associated with educational efforts, over half of the respondents said they use standard pre and post surveys and other learning assessment tools (i.e., at baseline, per session, or exit), one is developing an assessment protocol, and one conducts assessments "from time to time yes, when I get an intern I do is how it happens." One participant described the difficulty of tracking educational progress for youth that engage with program services periodically by saying, "Given the population we work with, depending on the home environment they're in, sometimes we won't see them for three months and then see them, or six months later we'll see them. We have an assessment tool we can use where it assesses them every quarter, but that hasn't been successful."

Diverse responses to a question regarding what they found to be most effective for educating youth include directly involving youth ("they don't like to be

talked to, they like to be talked with"), making lessons real-life related, and establishing trust.

***Youth client responses.***

*HIV service program responses.* All of the group interviews with youth from HIV service programs contained discussions about the ability to provide feedback for how their programs provide services, and youth within nearly all groups said the programs meet their educational needs. Among those that expressed an unmet educational need, youth from an HIV services program said adults need to address prevention for positives (i.e., preventing opportunistic infection among youth who have HIV and preventing infection of others).

Youth from HIV service programs said youth receptivity to HIV education depends on whether they are included, whether youth are comfortable with who is providing HIV education (e.g., "just having any random person comin' in and trying to teach this, it's not gonna be successful") and whether learning activities are interactive and fun. Suggestions for improving HIV education for youth included providing condoms and addressing myths (e.g., "Figure out what people already think about HIV and STDs and tell them 'This is right; That's wrong'").

Youth suggestions for improving HIV education include ensuring peer education (by age and youth who are HIV positive), updating educational materials to provide new, in-depth information, and addressing HIV education at earlier ages. The youth referred to their own school-related age of exposure to HIV education, and the majority said earlier is age-appropriate.

*At-risk service program responses.* All of the youth confirmed they are able to provide feedback for how their programs provide services, and three groups discussed a lack of receptivity among youth when adults to educate about HIV. For example, a participant said, "I don't even want to hear about it. You hear the same stuff over and over...they [adults] will say, 'If you do this you're gonna get HIV,' but they're not fully explaining it, so you don't really get it. Just boring." This statement refers to abstinence education, which suggests that the full explanation that is lacking includes sexual education or injection drug use.

Similar to the group interviews with youth from HIV service programs, youth from at-risk programs said that youth receptivity to HIV education depends on individual decisions and inclusion. Suggestions for improving HIV education for youth included having interactive activities, providing updated information (e.g., "The posters they have [are] like, 1990, 98...This is the 21st century!"), and using peer educators (by age and youth who are HIV positive).

***Archival materials.*** Six pamphlets and two HIV screening forms provided by program personnel illustrate how youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma. Only two HIV service programs use materials containing youth testimonials (e.g., "We're glad we got an HIV test. Get yours too. It's quick and easy"), and no forms request feedback to improve receptivity and effectiveness.

***Summary.*** Program personnel from HIV and at-risk programs each cited using some type of evaluation, especially informal, ad-hoc discussions that were

verified by all of the group interviews. However, HIV stigma reduction measures are not tracked or monitored in any of the programs despite acute awareness of how it detracts from HIV education. Program personnel can enhance youth receptivity to HIV education through youth inclusion (i.e., interactive activities and peer educators), according to youth from HIV and at-risk programs. Based on the responses regarding the effectiveness of HIV education, program evaluation of the perceptions and responses to the program structure and how it addresses HIV stigma can be enhanced by examining the timeliness of information, attaching formal and informal feedback mechanisms to materials, and determining age-appropriateness by ascertaining what youth wish they would have known about HIV earlier.

## **Chapter Five: Discussion**

### **Introduction**

The previous chapters provided a background on the role of HIV stigma in program implementation, in addition to a literature review, a discussion of the methods for qualitative data collection, and a detailed presentation of findings. The purpose of this chapter is to discuss the study's relevance, summary of findings, study limitations, and recommendations for future research and interventions.

Since there are no research studies informing program implementation of HIV stigma reduction by comparing adult educator and youth perspectives among programs that provide HIV services and those that provide at-risk services, this dissertation research is relevant to the interests of youth, program personnel, researchers, policymakers, and community advocates who observe that HIV stigma continues in the United States (Coalition for the Elimination of AIDS-related Stigma, 2010). For example, testimony on Capitol Hill for the most recent reauthorization of the Ryan White HIV/AIDS Treatment and Modernization Act contains a statement about HIV stigma from every expert witness and the congressional Chair of the Committee on House Oversight and Government Reform Henry Waxman (Ayala, 2008; Gerberding, 2008; Hauck, 2008; Holtgrave, 2008; Oldham, 2008; Siegel, 2008; Waxman; 2008). In addition, the President's 2010 National HIV/AIDS Strategy provides the following vision for care in the U.S.: "...every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic

circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination" (White House Office of National AIDS Policy, 2010).

Similar to the key terms associated with HIV/AIDS in the early 1980s, hostile and belligerent language is used to describe the disease. For example, congressman Pallone testified that continuance of the Ryan White program is "vital in our battle against this horrible epidemic" (Pallone, 2009). News articles continue to describe the *front line* fight in a *war* without a *silver bullet* or cure (e.g., McNeil, 2010). If the war meme is most appropriate, then Washington, D.C. is an HIV/AIDS hot zone resulting from multiple public policy wars--on drugs, poverty, illegal immigration, and crime--and youth in transition to adulthood are fighting for or against people living with the disease (Elbe, 2006; Eppright, 1998).

Alternately framing the disease as victimizing or the cause of suffering is not constructive, since this can raise oppositional group dynamics (i.e., guilty versus innocent victims). Youth who were born with HIV or were behaviorally infected are equally deserving of an education and a life without stigma.

HIV education can resolve misinformation, myths, and stigma to achieve peace and reduce social distance. However, front-line programs that provide HIV risk reduction and treatment services are addressing HIV stigma with constrained resources such as limited staff time, uncertain funding (sporadic, reduced, or restricted), and inflexible curricula. Individual personnel who rely on informal discussions and outdated materials lack a structure for systematic support. As a result, youth receive limited education to address and reduce stigma, inaccurate tailoring of program components to their unique needs, and inconsistent

evaluations of their perceptions and responses. While this dissertation research provides a foundation to inform program implementation of HIV stigma reduction, the following summary of findings, limitations, and recommendations for future research and interventions provide a sense of the considerable challenges for the youth-serving health and education fields.

### **Summary of Findings**

**Research question one.** *Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

Consistent with the observations in the late 80s about HIV stigma readily attaching to marginalized groups (e.g., Herek & Glunt, 1988), stereotypes and negative judgment by race, gender, and sexual orientation cited by the program personnel and youth clients shape the stigma surrounding HIV seropositive status within the sample of youth-serving human services programs in Washington, D.C. At present, these issues remain on the periphery of proscribed curricula regarding HIV transmission modes and risk factors.

These issues raise critical considerations regarding how HIV stigma is presented in curricula and instruction. For example, youth provided responses suggesting that accurate HIV education incorporates an understanding of youth language and its appropriate use. Without the direct involvement of youth in the creation or vetting of local HIV education, educational messages from adult program personnel may fail due to a lack of peer education and youth participation. While adults will likely continue to use professional or clinical terms in educational

program settings, they need to be aware of the variety of terms youth are using to refer to the disease since many of these terms reflect negative perceptions and misconceptions about HIV transmission.

Only two of the four program personnel from HIV service programs and none of the personnel from at-risk programs said there are positive aspects of having HIV. In comparison, youth from HIV service programs expressed positive aspects about the disease more often than youth from at-risk programs. Several youth from the at-risk programs provided specific examples of how youth with HIV are stigmatized, and in one instance a youth felt stigma to such an extent that he severed a friendship and had nightmares.

***Research question two.*** *How do individual program components (goals, objectives, and activities) address HIV-status stigma?*

Individual program components address HIV-status stigma through porous institutional policies, proscribed curricula, confidentiality concerns, and in one instance stigma among program personnel. Condoms are more accessible from the HIV programs than the at-risk programs, despite an overarching awareness of youth sexuality and widespread youth misperceptions about HIV transmission among program personnel from all of the programs.

While HIV program personnel cited fewer constraints to deliver educational content than the at-risk program personnel, they are not paid by their programs to deliver instructional material beyond the proscribed curricula. One implication of this constraint is the relegation of HIV stigma to a hidden curriculum. While specific program personnel are aware of pervasive HIV stigma and frequently hold informal



conversations with youth, this expertise can be lost through staff turnover or individual time constraints. Awareness of HIV stigma among youth can be similarly lost when they disengage with these programs, graduate, or age out.

While archival materials have a role in HIV messaging, many gathered for the study are outdated and do not cover the information the youth said they need. Involving peer educators in curricular updates, especially since social media are evolving, can improve outreach activities, engagement with youth for HIV screening and treatment, and risk reduction messaging.

***Research question three.*** *How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?*

The identification of the target client through HIV disclosure, HIV testing, and open communication about HIV-related adversity shapes the way youth-serving human services programs address HIV-status stigma. The majority of the terms youth use to refer to HIV (e.g., the 30-day notice, house of pain) are especially indicative of why youth avoid identifying with HIV. The fear of negative treatment from family members, friends, and intimate partners prevents program personnel from knowing how to adjust and individualize curricula and instruction.

HIV service programs are established places for youth to obtain HIV testing or condoms, and it is typical that program personnel within these programs are open about being HIV positive or maintain close relationships with others who have HIV. At-risk programs rely on trust and comfort to talk openly about HIV with their youth clients and do not provide as much open access to condoms. In addition,

program personnel living with HIV are less frequent among at-risk programs. No archival materials provided by personnel address HIV stigma and illustrate several disconnects between their depictions and target clients' characteristics by race, ethnicity, gender, and sexual orientation. For example, one pamphlet contains images of youth with an accompanying statement that reads, "The models have no relation to the story or issue presented."

***Research question four.** How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?*

Program personnel frequently use informal assessments more often than formal assessments to verify youth receptivity. As a result, many assessments are passive and depend on youth to voice a complaint or initiate a discussion. Despite this limitation, most of the youth participating/enrolled in HIV and at-risk programs hold positive views of their program structures and how they generally address HIV overall.

None of the archival materials solicit feedback, and the link between data gathered from formal evaluations and program tailoring is unclear, particularly within the at-risk programs. The use of needs assessment data to specify the number and type of clients served also varies across programs depending on individual interests and administrative concerns.

### **Study Limitations**

The primary limitations to the methodological and analytical rigor of this study include differential responses to prompts and response biases related to

withholding information or providing information participants deemed socially desirable. Within the group interviews with youth, there were attempts by some participants to dominate the discussion by talking over others. I interrupted, reframed, and selectively called on participants while maintaining a neutral demeanor to maintain the flow of the group interviews. While all questions were asked and answered within the time for data collection, participant response bias due to social desirability was outside of my control. In addition, the results of this case study can only be applied to the purposive and narrowly focused sample of programs that provided data for the study.

### **Recommendations for Future Research and Interventions**

To accurately address how HIV stigma is evolving, additional research and educational programming in Washington, D.C., is vital. Given the findings of this study, there are significant opportunities for programs to align with the theoretical models and program guidance discussed in Chapter two. For example, the *HIV Stigma Framework* provides a way for program personnel to create stigma reduction interventions. This study's findings confirm that HIV stigma operates in distinct ways among those who are infected and uninfected with HIV. Re-examining this framework in Figure 5, prejudice, HIV stigma is a catalyst for a cascade of mechanisms and outcomes.

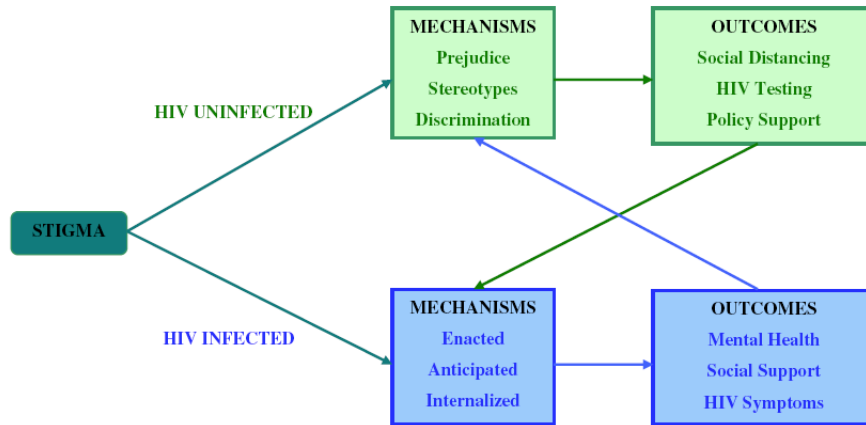


Figure 5. The HIV stigma framework. From “From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures” by Earnshaw, V. A., & Chaudoir, S. R., 2009, *AIDS and Behavior*. Copyright 2009 by Springer. Reprinted with permission.

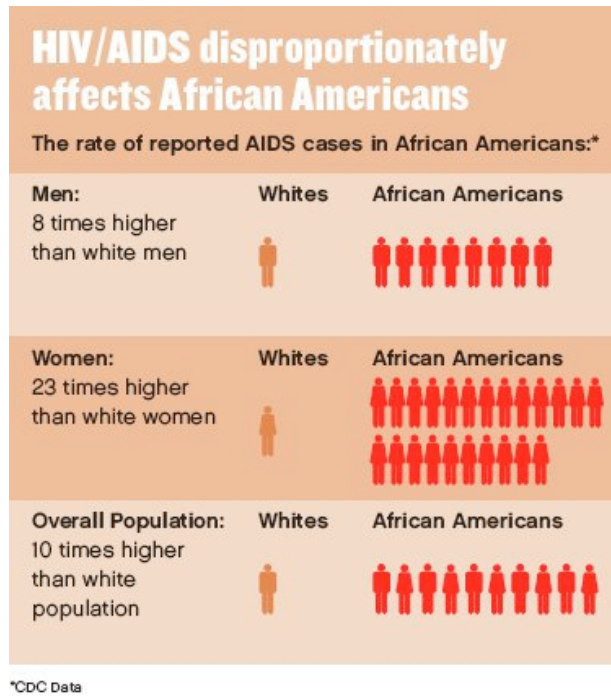
Among the HIV uninfected (at-risk youth), HIV stigma was found to intertwine with prejudice, stereotypes, and discrimination and result in social distancing. For example, one youth said he severed a relationship after finding out this friend had HIV and then provided the analogy, "like if your friend a faggot, it's gonna change the way you see him." This statement is a clear example of the negative terms youth use to discriminate against others.

The framework also addresses mechanisms (enacted, anticipated, and internalized HIV stigma) and outcomes (diminished mental health, decreased social support, and increased HIV symptoms) among HIV infected individuals. Youth provided several example of internalized HIV stigma or having witnessed stigma enacted toward others. The youth said that youth would experience stigma if they were to disclose their HIV positive status to friends, family members, or intimate partners. To counteract this lack of social support, program personnel may want to

address the internalized feelings and the events that were witnessed for youth to feel more comfortable about seeking social support. This approach is supported by Herek and Glunt's (1988) model of stigma reduction that includes taking the time to think about one's actions, evaluating the circumstances of the individual one is stigmatizing, and considering social standards where prejudice is not accepted.

Youth described several educational needs, including making lessons interactive and fun. The pedagogical methods suggested in the literature and program guidance discussed in chapter two include gaming. Program personnel may want to use these activities for youth to separate HIV transmission myths from facts. Herek and Glunt (1988) argued for curriculum that addresses not only how HIV transmission occurs, but also how it does not occur. This approach was corroborated by a youth participant from an HIV service program in this study who said, "Figure out what people already think about HIV and STDs and tell them 'This is right; That's wrong.'"

Educational gaming may have the advantage of making the topic of HIV stigma more approachable. A number of possible games can be constructed and played by youth, such as matching or selecting among myths and facts. Games using infographics can illustrate the burden of the disease among specific populations served by programs. For example, Figure 6 illustrates the disproportionate number of African Americans with HIV/AIDS. The statements on the left can be separated from the images on the right, and then youth can be asked to match these correctly. They can also create a similar infographic for Washington, D.C.



*Figure 6.* Rate of reported AIDS cases in African Americans. From “National Black HIV/AIDS Awareness Day,” 2011, *NIAID*.

Program activities related to digital media are of interest to many youth, as evidenced by the youth statements regarding Facebook and YouTube. The accessibility of information stored on flash drives was also found to help one program, which can be replicated by other programs.

Since all of the programs in this study do not have a consistent structure for addressing HIV stigma, Table 6 provides a template for short and long-term structural change objectives (SCOs) that are useful for individualizing HIV stigma services and supports through professional development, peer education among youth, youth participation, and community networking. SCOs provide a mechanism for continuous quality improvement, and demonstration programs can successfully use SCOs to build program capacity and service system infrastructure (Ziff et al.,

2010). By applying specific, measurable, achievable, realistic, and time-framed (SMART) criteria to this framework, program personnel and youth can take ownership and accountability, report successive achievements, and work collaboratively to resolve barriers.

Macro, system level institutionalization (i.e., prioritization and funding) of these objectives can be achieved by incorporating HIV stigma reduction into federal funding opportunity announcements, project officer implementation guidance, and national evaluation team and think tank action plans (e.g., National Network to Eliminate Disparities Transition to Independence Learning Cluster). Since non-profit organizations have a competitive advantage when they apply for federal, state, or local funding as a collaborative network, program level institutionalization of the objectives can facilitate cross-program alignment.

Table 6

*Cross-Program Structural Change Objectives*

	<b>Due date</b>	<b>Recommended activities</b>	<b>Measures of success</b>	<b>Person(s) responsible</b>
<b>Short-term SCOs</b>				
1. Change job descriptions to include HIV stigma reduction	TBD	Modify hiring announcements and consultant contracts; amend employee files	All forms updated	Administration, HR
2. Train all personnel on HIV stigma reduction	TBD	Schedule mandatory training	Attendance via sign-in sheets complete; Training evaluations indicate all learning objectives met	Program coordinator
3. Establish peer education between youth served by HIV and at-risk programs	TBD	Facilitate youth participation in an e-learning product (webinar, webcast)	e-learning evaluation indicates all learning objectives met	Program manager & coordinator
4. Establish mentoring between youth served by HIV and at-risk programs	TBD	Facilitate youth mentoring to create prevention, testing, and medical adherence materials	# of youth participating; youth co-presentation at two professional meetings	Program manager & coordinator



	<b>Due date</b>	<b>Recommended activities</b>	<b>Measures of success</b>	<b>Person(s) responsible</b>
<b>Long-term SCOs</b>				
5. Update HIV educational curricula to include stigma	TBD	Review materials	All materials have expiration dates and are current	Program manager & coordinator
6. Evaluate personnel and client HIV stigma at least annually	TBD	Amend employee annual evaluations and entrance/exit interviews; update client satisfaction surveys	Increased monitoring of stigma; established agenda item at employee meetings	Administration, HR, program manager
7. Sustain a youth-led community advisory council	TBD	Establish regular meetings	# of youth council members; diversity of representation; participation consistency	Program coordinator
8. Create a stigma reduction scholarship award	TBD	Budget for awards/engravings; establish scholarship fund; Schedule award celebration event	# of community partners; target amount of funding raised	Board of directors; administration, development & finance depts.

**SCOs to address program limitations elicited by research question one.**

*Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

Since the findings of this study suggest that HIV stigma reduction is tangential to their responsibilities or largely informal, modifying job descriptions is a first step toward changing staff expectations. This short-term, administrative objective includes modifying hiring announcements and consultant contracts, in addition to amending employee files.

The second SCO is to train all personnel on HIV stigma reduction. Since personnel may not be aware that they are contributing to stigma through their avoidance or silence, mandatory training would focus on case-based examples of how prejudice, stereotypes, and discrimination toward HIV positive individuals interacts with poor psychological, social, and physical outcomes. Prominent examples taken from this study can include youth that express having nightmares and poor social interaction as a result of HIV stigma. During part of this training, a role-play demonstration of how to address HIV stigma may include how unnecessary, extraordinary precautions when interacting with HIV positive youth have changed since the early 1980s.

**SCOs to address program limitations elicited by research question two.**

*How do individual program components (goals, objectives, and activities) address HIV-status stigma?*

The third SCO is to establish peer education between youth served by HIV and at-risk programs. Since this study found that youth desire peer education and

suggest using online social media, program personnel can facilitate the co-production of an e-learning webinar on HIV stigma reduction by youth from an HIV program and at-risk program. Hopelessness and fears about HIV among some at-risk youth in particular may resolve through co-production across program types.

The fourth SCO is to establish mentoring between youth served by HIV and at-risk programs. Pairing mentors who have lived with HIV or have family, friends, or intimate partners with HIV with at-risk youth to create HIV stigma reduction messages for HIV prevention, testing, and medical adherence materials would provide intergenerational transference across program types. Presentation of these materials at two professional meetings would provide the opportunity for youth to gain networking, professional speaking, and organizational skills.

#### **SCOs to address program limitations elicited by research question**

**three.** *How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?*

Since this study found outdated materials within programs, the fifth SCO is to update HIV educational curricula to include stigma. Having a curriculum that includes transmission risks *while* addressing stigma reduction is an ideal reflected in the research literature, and youth would have the opportunity to select among a mix of activities (e.g., group discussion, role-play exercises, gaming, and problem solving) that would most interest them.

All curricular materials can include expiration dates in addition to creation dates. Youth participation in the review of these materials and the creation of new materials can address their contemporary concerns. For example, a youth who

incorrectly depicts a youth living with HIV for an educational pamphlet or website by illustrating bumps or frailty would provide a discussion about the need for changing perceptions.

**SCOs to address program limitations elicited by research question four.**

*How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?*

Since this study found uneven evaluation and a lack of emphasis on HIV stigma, the sixth SCO is to evaluate personnel and client HIV stigma at least annually. Personnel entrance interviews, annual merit/performance evaluations, and exit interviews are three ways to evaluate personnel HIV stigma. Client intake surveys, client feedback forms (pre-stamped, pre-addressed), and annual satisfaction surveys can similarly increase surveillance of HIV stigma. Community service hours required by high schools, scholarships, and college entry prerequisites are potential sources of peer engagement in this activity.

The seventh SCO is to sustain a youth-led community advisory council to address HIV stigma by reviewing policies, program materials, and surveillance data. By establishing regular meetings and maintaining consistent, diverse youth participation, youth will have a platform for providing direct input into program services. Programs personnel also will gain an important mechanism for enhancing compatibility with the cultural and linguistic characteristics of their community's population (Hernandez, Nesman, & Isaacs, 2008).

The final SCO is to create a stigma reduction scholarship award. Honoring outstanding educational efforts to address HIV stigma is a way to engage youth, program personnel, and community supporters. An engraved award, scholarship fund, and celebration event draws media attention to the importance of the issue and provides direct assistance for education. In addition, community supporters gain a mechanism for donations and a venue for professional networking.

### **Conclusion**

To create a system of care to address HIV stigma across multiple programs serving similar youth (or in many instances the same youth at different times), youth programs need to institutionalize expectations, training, youth networking, and community support through structural changes. Given an increasing HIV infection rate among youth and the continuing social distance toward people living with HIV, program personnel and youth clients need to transform silence and threats into recognition and education.

Following the completion of this dissertation, opportunities for cross service-system institutionalization of HIV education for youth in transition to adulthood include the following:

1. Conducting further research to replicate and expand the case study method by region and by service systems (e.g., juvenile justice, substance abuse and mental health, homelessness, foster care and transitional living);
2. Gaining research assistance by employing community liaisons, particularly minority youth who are HIV positive to deliver address their negative experiences and concerns;

3. Delivering training on health outcomes research and evaluation methods for program staff to closely monitor the continuous quality improvements of their program's processes and outcomes;

4. Wide dissemination of findings in the research and professional literature; and

5. Expanding existing coalitions through Howard University (one of 105 historically Black colleges and universities), Howard University Hospital that serves HIV positive minority youth in Washington, D.C., the National Association of People with AIDS (NAPWA) and other member-driven advocacy organizations, the University of South Florida Division of Infectious Diseases and International Medicine that serves HIV positive youth (most of whom are minority youth), the Coalition to Eliminate AIDS-related Stigma, the National Youth Advocacy Coalition, the National Network to Eliminate Disparities in Behavioral Health, and other organizations, federal agencies, and national quality improvement teams devoted to the collective understanding of race, gender, sexual orientation, ethnicity, and culture to prevent and address marginalization of people living with disease, illness, injury, and disability.

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## **Appendices**

## **Appendix A: Program Letter of Support Template**

The following template was placed on agency letterhead and signed by program administrators to indicate support for this study. Table 7 illustrates the programs that are providing HIV services for HIV positive youth and programs that are providing risk reduction services for youth whose HIV status is not explicitly identified.

**DATE:**

**TO:** University of South Florida (USF) Institutional Review Board

**FROM:** [Agency name]

**SUBJECT:** Letter of Support

We are supportive of the research study *HIV Education for Youth in Transition to Adulthood*.

The Ph.D. candidate and researcher Peter Gamache has approval to conduct interviews with program personnel and/or hold focus groups with youth participants (ages 13-24) at our facility for the pilot and/or implementation phase of the study. The research plan has been reviewed and found appropriate for the population targeted at our facility.

Appropriate resources will be available in the form of the use of a private room for one hour to allow the investigator to conduct research in the IRB approved manner. No unanticipated/adverse events are expected to occur during this event given the risks associated with the research, and there are adequate provisions in place to handle unanticipated/adverse events.

Sincerely,

[Program administrator name, title, and contact information]



Table 7

*Programs by Service Type*

<i>HIV Services</i>	<i>At Risk Services</i>
1. HIV testing and primary medical care <sup>2 3</sup>	1. Homeless, runaway, life skills <sup>2 3</sup>
2. HIV testing and case management <sup>5</sup>	2. Foster care, mental health, life skills <sup>2 3</sup>
3. AIDS service organization <sup>3 4</sup>	3. Counseling, life skills for teen mothers <sup>2 3</sup>
4. HIV testing and primary medical care <sup>3</sup>	4. Supportive housing services <sup>5</sup>
5. AIDS service organization <sup>2 3</sup>	5. Foster care, teen leadership services <sup>2 3</sup>

<sup>2</sup> Provided one interview for the study

<sup>3</sup> Provided one group interview for the study

<sup>4</sup> Provided two interviews for the study

<sup>5</sup> Pilot study program

## **Appendix B: Interview Protocol**

*Note.* Interview participants (program staff) will be required to provide informed consent before any interview begins. Peter Gamache, the Interview facilitator, will verify understanding, will be able to explain the forms and answer any questions, and will ensure all forms are signed.

Now that you've read through the adult informed consent form, do you have any questions? Were you able to read and understand all of the items on the form? [verify consent form is signed by the participant and sign the Statement of Person Obtaining Informed Consent].

### *Introduction (2 minutes)*

This is Peter Gamache speaking. The time and date is \_[\_:\_]\_am/pm on \_\_\_[day/month]\_\_\_, 2010, and I am speaking with \_\_\_[name]\_\_\_ from \_\_\_[program]\_\_\_\_\_.

Thank you for meeting with me today. Before we begin, do I have permission to record this interview? Do I have your informed consent to take part in the research study entitled, *HIV Education for Youth in Transition to Adulthood*?

My role today is to ask a set of questions about HIV stigma among youth in your program. You are the expert, and I am here to learn from you. You will be asked to discuss the reasons underlying why HIV stigma within programs is avoided in some instances and addressed in others, how your program is set up to address HIV stigma, how HIV stigma is addressed based on which specific youth receive program services, and how you believe youth perceive how your program addresses HIV stigma.

You were asked to provide an interview because you are a service provider of [HIV positive youth] or [youth that are considered at-risk for HIV]. Please do not share the following questions or your responses with other program personnel or youth who may take part in this study, since the intent of the interviews is to gain open-ended, spontaneous responses rather than preconceived answers. Also, please do not mention names or any other identifying characteristics of the youth you serve.

### *Questions: Warm-up (5 minutes)*

#. Can you please tell me about why you work for your organization?  
Why do you work with youth?

- #. How long have you been in your current position?
- #. When did you first hear about HIV?
- #. How do people talk about HIV in the local area?
  - #. What are the negative words that are associated with HIV?
  - #. Are there positive words associated with HIV?

*Questions: Used to Answer Primary Research Question One (12 minutes)*

*Primary Research Question One: Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

- #. Are youth with HIV stigmatized?
  - #a. How are they treated?
  - #b. Are they avoided?
  - #c. Are they separated?
  - #d. Are they feared?
  - #e. By whom?
- #. Are youth who have HIV stigmatized differently by race, ethnicity, gender, or sexual orientation?
  - #. Are there other influential characteristics?
  - #. Are there stereotypes?

- #. What happens to youth when it is known that they have HIV?

*Questions: Used to Answer Primary Research Question Two (12 minutes)*

*Primary Research Question Two: How do individual program components (goals, objectives, and activities) address HIV-status stigma?*

- #. How does your program provide support for people with HIV?
- #. Does your program specifically address HIV stigma?
  - If yes,
    - #a. How?
    - #b. Why?
    - #c. In what situations?
  - If no,
    - #c. Why doesn't your program address HIV stigma?

- #. Are there institutional limits on the ability of program personnel to address HIV stigma?

- #. Are there peer norms that prevent communication about HIV?
- #. What enhances the ability of program personnel to address HIV stigma?
- #. What is/are the overall goal(s) of your program?
- #. What is/are the overall objective(s) of your program?
- #. What are the overall activities of your program?
- #. Are there client needs related to HIV that your program is unable to address?
- #. Are there any changes you would like your program to make to address client needs related to HIV?

Questions: Used to Answer Primary Research Question Three (12 minutes)  
Primary Research Question Three: How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?

- #. Do you think any of your youth clients would have concerns about disclosing they have HIV?

If yes,

- #. To whom?

Family?

Friends?

Intimate partners?

- #. Are youth with HIV identified by your program?
  - #a. How?
  - #a. What are the common characteristics of youth with/without HIV in your program?

- #. Is there a priority group that is most “at-risk” for HIV?

- #. Was needs assessment or other data used to specify the number/type of clients served by your program?

- #. Does community planning input inform how your program provides services?

Questions: Used to Answer Primary Research Question Four (12 minutes)  
Primary Research Question Four: How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?

- #. Do your youth clients provide feedback for how your program provides services?

#a. How?

#. How do your youth clients perceive your services?

#. Is there a difference by age (i.e., developmental differences)?

#. Are youth receptive to your efforts to educate them?

#. Do you measure changes associated with educational efforts?

#. What have you found to be most effective for educating youth?

Questions: Wrap-up (5 minutes)

#. Is there any other feedback you'd like to share about youth, HIV stigma, or your program?

Thank you for your time!

For the pilot phase interviews, additional questions were:

- Since this is a pilot study, do you think that others who are similar to yourself will respond to the questions I've asked?
- Do any of the questions need to be changed to find out what others who are similar to yourself think?
- Did you have the opportunity to talk about what is important to you?
- Are there questions that should be added/omitted?
- Which questions did you need to think about the most/least?
- Are there better ways that the questions could be asked?

## Appendix C: Group Interview Protocol

Note. Group interview participants will be required to provide informed consent (if 18+) or assent (if 13-17) before any group interview begins. Peter Gamache, the group interview facilitator, will verify understanding, will be able to explain the forms and answer any questions, and will ensure all forms are signed.

Now that you've read through either the consent/assent form, do you have any questions? Were you able to read and understand all of the items on the form? [verify consent/assent form is signed by the participant and sign the Statement of Person Obtaining Informed Consent/Assent].

### Anonymous group check-off form

Please select your

#### Age

- |                             |                             |
|-----------------------------|-----------------------------|
| <input type="checkbox"/> 13 | <input type="checkbox"/> 19 |
| <input type="checkbox"/> 14 | <input type="checkbox"/> 20 |
| <input type="checkbox"/> 15 | <input type="checkbox"/> 21 |
| <input type="checkbox"/> 16 | <input type="checkbox"/> 22 |
| <input type="checkbox"/> 17 | <input type="checkbox"/> 23 |
| <input type="checkbox"/> 18 | <input type="checkbox"/> 24 |

#### Gender

- Male
- Female
- Transgender

#### Race/Ethnicity

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Hispanic or Latino

Other (please specify): \_\_\_\_\_

This form will not be connected to your name or any other identifying characteristics.



### Introduction (2 minutes)

Good morning/afternoon, and welcome to our session. Thank you for taking the time to join for a discussion today about how youth such as yourselves react to the Human Immunodeficiency Virus (HIV).

My name is Peter Gamache, and I am a student at the University of South Florida (USF). What you will say today in this discussion group, or group interview, is part of what I will use for a study on HIV education for youth in transition to adulthood. My role today is to guide the discussion and not participate.

You are the experts, and I am here to learn from you. You will be asked to discuss how often HIV is talked about or not talked about, reactions to people who have HIV, and the best and worst ways for educators to help people understand HIV and prevent infection.

You were all invited because you are connected to a program serving youth. Before we begin, please let me mention some ground rules.

1. Please try to **speak as clearly as possible** since we are recording this group interview.
2. What you say today will **not be attached to your identity** in this study's final report. I will write about how many people in this room are of a certain age, gender, and race/ethnicity, but beyond that I do not know who you are and do not need any names. Anything personal that is said will not be used, and I assure you **complete anonymity**.
3. Please **respect the privacy** of other participants by not discussing who is in attendance and what they say. Also, please **do not discuss** the following questions to other youth who may take part in this study, since the intent of the group interviews is to gain open-ended, spontaneous responses rather than preconceived answers. Also, please do not mention names or any other identifying characteristics about yourself or others.
4. I would like to make sure that **each of you gets a chance to speak**. There may be times throughout the discussion that I may interrupt you, since we have a lot to cover, but please feel free to let me know if you need more time to finish your thoughts. Please do not interrupt others who are trying to speak.

There are no right or wrong answers, but rather differing points of view. Please feel free to share your point of view if it differs from what others have said. In this session, it is important that everyone fully participates. Everyone is an important resource.

Our session today will last about one hour, and we will not be taking a formal break. In the event you may need to use the restroom at any time, they are located [indicate location].

*[The following questions will be pre-written in large, block letters on a flip chart to save time]*

*Questions: Warm-up (5 minutes)*

Let's find out more about each other's experiences by going around the room one at a time. The first questions to get us started are:

- #. When was the first time you heard about HIV, the Human Immunodeficiency Virus?
- #. How do people talk about HIV in the local area?
  - If yes,
  - #. What are the negative words that are associated with HIV?
  - #. Are there positive words associated with HIV?

*Questions: Used to Answer Primary Research Question One (12 minutes)*

*Primary Research Question One: Within metropolitan youth-serving human services programs, what shapes the silencing or addressing of stigma surrounding HIV seropositive status?*

- #. Are youth with HIV stigmatized?
  - #a. How are they treated?
  - #b. Are they avoided?
  - #c. Are they separated?
  - #d. Are they feared?
  - #e. By whom?
- #. Are youth who have HIV stigmatized differently by race, ethnicity, gender, or sexual orientation?
  - #. Are there other influential characteristics?
  - #. What is the influence of media (radio stations, television, posters)?
  - #. Are there stereotypes?
- #. How are people with HIV identified?
  - #. What does someone with HIV most commonly look like?
- #. What happens to youth when it is known that they have HIV?

*[Participants will be instructed to share their ideas, round robin approach]*

*[Moderator is to record and number ideas on the flip chart. If the list takes up more than one page on the flip chart, I will need to tape the sheets of paper to the wall so all listed items can be in plain view of participants]*

*[Participants will be instructed to share their ideas as a group following initial responses]*

*[Moderator will summarize and validate responses in vivo]*

Questions: Used to Answer Primary Research Question Two (12 minutes)  
Primary Research Question Two: How do individual program components (goals, objectives, and activities) address HIV-status stigma?

Now we are going to go through a similar process, but with a new topic. I want to talk about the programs you attend.

- #. How often is HIV talked about in programs?
- #. If an adult from a program wanted to educate youth about HIV, what would make this easier?
- #. Do you think written materials are helpful?
  - #. Are there differences by age?
- #. Do you think pictures are helpful?
  - #. Are there differences by age?
- #. Would these materials help to create a better environment to educate about HIV?
- #. How was the topic of HIV addressed at your schools?
- #. What can educational programs do that they aren't doing now?

Questions: Used to Answer Primary Research Question Three (12 minutes)  
Primary Research Question Three: How does the identification of the target client by youth-serving human services programs shape the way a program addresses HIV-status stigma?

- #. Do you think youth would have concerns about disclosing they have HIV?
  - If yes,
    - #. To whom?
      - Family?
      - Friends?
      - Intimate partners?
- #. Is there a priority group that is most "at-risk" for HIV?
  - #. What are the common characteristics of youth with/at-risk for HIV?
  - #. Are there stereotypes?

Questions: Used to Answer Primary Research Question Four (12 minutes)  
Primary Research Question Four: How do youth participating/enrolled in youth-serving human services programs perceive and respond to the program structure and how it addresses HIV-status stigma?

- #. Are you able to provide feedback for how your program provides services?
  - #a. How?

#. What do you think of these services (i.e., do they meet your educational needs)?

#. When adults try to educate you about HIV, are youth receptive?

#. What could they do better?

*Questions: Wrap-up (5 minutes)*

This is what we talked about [*review flip chart items*].

#. Is there any other feedback you'd like to share about youth, HIV stigma, or your program?

Thank you for your time!

For the pilot phase group interviews, additional questions were:

- Since this is a pilot study, do you think that others who are similar to yourself will respond to the questions I've asked?
- Do any of the questions need to be changed to find out what others who are similar to yourself think?
- Did you have the opportunity to talk about what is important to you?
- Are there questions that should be added/omitted?
- Which questions did you need to think about the most/least?
- Are there better ways that the questions could be asked?

*Group Interview Participant Recruitment Flyer Template*

**Group Interview Participants Ages 13-24 Needed !!!**

Participate in a group interview as part of a research study to discuss  
health education

A \$25 stipend in the form of a gift card will be presented to each  
participant in appreciation of the time given to this study

Scheduled group interviews:

[Day, Month ##, Year from 5:30-6:30pm]

**Location [address/map image]**

Call Program Personnel at (**clinic #**) to reserve your place in one  
of these group interviews.

Your participation is extremely important!

This study has been approved by the University of South Florida Institutional Review Board: # Pro0001119

## Appendix D: Archival Materials Protocol

### *Archival Materials Data Abstraction Tool*

---

Material(s) type:

- Pamphlet  
 One-sheet  
 Poster  
 Other (specify): \_\_\_\_\_  
 None

Intended audience(s):

- Parent  
 Student  
 Professional  
 Other (specify): \_\_\_\_\_

Publication source/creator: \_\_\_\_\_

Funding source: \_\_\_\_\_

### **Text**

Title: \_\_\_\_\_

Background color(s): \_\_\_\_\_

Font size(s): \_\_\_\_\_

Font color(s): \_\_\_\_\_

Number of words

Per page: \_\_\_\_\_

Per section: \_\_\_\_\_

Statement type(s):

- Directive  
 Informative  
 Inquiry

Risk factors/transmission modes:

- Bodily fluids  
 Injection drug use  
 Sexual contact/intercourse  
 Other (specify): \_\_\_\_\_

Prevention methods:

- Avoidance of alcohol  
 Avoidance of drug use

- Avoidance of unprotected sex
  - Abstinence
  - Condoms/barrier protection
  - Fidelity
- HIV testing
- Other (specify): \_\_\_\_\_

Signs and symptoms of HIV/AIDS: \_\_\_\_\_

Assumptions/Myths: \_\_\_\_\_

Follow-up contact information (specify): \_\_\_\_\_

**Images/depictions**

Object type(s): \_\_\_\_\_

Demographics

Age: \_\_\_\_\_

Race/ethnicity: \_\_\_\_\_

Gender:

- Male
- Female
- Transgender

Sexual orientation

- Heterosexual
- Lesbian
- Gay
- Bisexual
- Transgender
- Questioning
- Other (specify): \_\_\_\_\_
- Unknown

Placement/location(s):

- Shelving
- Display table
- Other (specify): \_\_\_\_\_

Number/availability of materials: \_\_\_\_\_

Are HIV/AIDS materials co-located with other materials?

- Yes
- No

If Yes, specify types: \_\_\_\_\_

Does the program have more in stock but not on display?

- Yes
- No

If Yes, how many of each type? \_\_\_\_\_

## **Appendix E: A Priori Coding Framework Operational Definitions**

### ***Program Barriers to Address HIV***

**Capacity** - program resources (e.g., time, personnel) to address HIV (Sieverding et al., 2005).

**Policy restrictions** - proscribed, codified program processes that prohibit addressing HIV or risks associated with HIV (Bowler, Sheon, D'angelo, & Vermund, 1992).

**Confidentiality concerns** - beliefs among program personnel that client confidentiality outweighs the ability to address HIV (Lehrer, Pantell, Tebb, & Shafer, 2007).

**Curricular limitations** - restrictions on what can be said or written about HIV within an educational setting or lesson (Bowler, Sheon, D'angelo, & Vermund, 1992).

**Personnel stigma** - stigma held by program personnel toward clients or others (Klein, Karchner, O'Connell, 2002).

### ***Current Program Components***

**Abstinence** - the message to not have sex (Jemmott, J., Jemmott, L., & Fong, 2010).

**Condoms** - the distribution or reference to condoms (Johnson, Carey, Marsh, Levin, & Scott-Sheldon, 2003; Reece et al., 2010).

**Referrals** - written or verbal suggestion for clients to connect with HIV-related resources outside of a program (Lin, Melchiono, Huba, & Woods, 1998).

**Outreach** - sending personnel or messages into local neighborhoods or communities to initially engage or re-engage clients by offering program services (Sion et al., 2003).

**Testing** - using a biological sample to detect for the presence of HIV (Goodman et al., 1999).

**Social support** - providing encouragement, resources, and an understanding of one's struggles and achievements related to HIV (Lam, Naar-King, & Wright, 2007).

**Partner notification** - contacting individuals in a client's sexual or social network to notify them about their risk for HIV (O'Brien et al., 2003; Rotheram-Borus & Futterman, 2000).

**Peer education** - education provided by individuals with perceived similar characteristics (e.g., age, race, ethnicity, gender, sexual orientation, language) (Pearlman, Camberg, Wallace, Symons, & Finison, 2002).

**Lesson plans/curricula** - proscribed oral or written information about HIV within a program's educational structure (Pedlow & Carey, 2003).

**Formal client feedback** - gathering written information or verbal testimony from clients about the quality of program services and following a codified process of reviewing this information for potential improvements (e.g., evaluation forms, a suggestion box) (Harper, Neubauer, Bangi, & Francisco, 2008).

**Informal client feedback** - asking for verbal responses from clients about the quality of program services and following an ad-hoc process to evaluate the merits of this feedback (Harper, Neubauer, Bangi, & Francisco, 2008).

**Inviting community input** - information provided by a community member or group regarding the quality of program services to suggest potential improvements (Wu & Martinez, 2006).

### ***Program Suggestions to Address HIV***

**Openness to discuss** – the ability to engage in dialogue about HIV and its related risk and resiliency factors (Pearlman, Camberg, Wallace, Symons, & Finison, 2002; Talashek, Peragallo, Norr, & Dancy, 2004).

**Curricular flexibility** - the ability of program personnel to deviate from a proscribed curriculum to explore extant topics or apply innovative teaching methods (Haignere, Culhane, Balsley, & Legos, 1996; Senderowitz & Kirby, 2006).

**Facilitator skill** - experience, understanding, or application of concepts unique to individual program facilitators (Messias, Fore, McLoughlin, & Parra-Medina, 2005).

**Facilitator characteristics** - behaviors or characteristics unique to individual program facilitators (e.g., race, ethnicity, gender, sexual orientation, language) (Messias, Fore, McLoughlin, & Parra-Medina, 2005).

**Community networking** – situating the program as part of a larger collective focused on HIV (e.g., member of a community advisory panel, hosts or participates in workgroups) (Dworkin, Pinto, Hunter, Rapkin, & Remien, 2008).



**Client incentives** - tangible and intangible offerings for clients to engage in program services (e.g., money, entertainment, transportation) (CDC, 2006c).

**Use of data** - the gathering or synthesis of specific HIV-related variables (e.g., statistical reports, epidemiological profiles, service utilization trends) (National Quality Forum, 2009).

**Developmental appropriateness** - delineation of HIV information based on stages of growth (e.g., biological age, psychological readiness) (Pedlow & Carey, 2004).

**Safe space** - a physical location to discuss HIV free from harm (Slesnick & Kang, 2008).

### ***Client Barriers to Address HIV***

**Stigma** - discrediting the value of a person (external stigma) or one's-self (internal stigma) based on a negative social status position (Link & Phelan, 2001; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007).

**Myths** – stories used to explain how or why HIV exists (e.g., the origin of HIV or the reasons people have HIV) (Keselman, Kaufman, & Patel, 2004).

**Lack of social support** - a lack of social capital resulting in isolation (Coleman, 1988).

**Misinformation** - factually incorrect information about HIV (e.g., physiological mechanisms of transmission) (Singh, 1994).

**Denial** – a reaction to HIV that includes withholding information or resources concerning its existence (Kubler-Ross, 1987).

**Fear** - feeling imminent self harm in the proximity or interaction with someone with HIV (Brown, Macintyre, & Trujillo, 2003; Doka, 1997).

**Self-blame** – self-perceived punishment for wrong-doing (Miller & Major, 2000).

**Cultural norms** – behaviors or beliefs ascribed to either a demographic or self-identifying characteristic of a larger group (e.g., language) (U.S. Office of Minority Health, 2001; Wilson & Miller, 2003).

**Negative treatment** – harmful actions toward people living with HIV (Kaplan, Scheyett, & Golin, 2005).

## ***Views of HIV***

**Preventative** - primary, secondary, or tertiary prevention of HIV. Primary prevention includes reducing risks for contracting the disease; secondary prevention includes screening for the disease after a risk exposure (e.g., unprotected sex, injection drug use); tertiary prevention includes the avoidance of opportunistic infections (Mayer & Pizer, 2009).

**Death sentence** - the view that closely associates HIV with death despite the potential to live healthy with HIV (Sontag, 1997).

**Hopeless** - the view that obstacles outweigh the potential to address HIV (e.g., a perception that living with HIV is consistently negative or painful without abatement; a belief that nothing can be done to reduce HIV infection) (Dickerson, 1994; Kubler-Ross, 1987).

**Stereotypes** - generalizations and expectations about a group of people perceived to have similar characteristics (e.g., inaccurate beliefs about common behaviors of others, the types of people who contract disease, and how others think because they are part of a group are seen without exceptions) (Sue, 2001).

**Discrimination** - actions resulting in the diminishment of an individual's or group's standing based on perceived characteristics associated with HIV. Actions separating "us" from "them" can result in harassment, violence, de-humanization, and segregation (Parker & Aggleton, 2003).

**Second chance at life** - turning one's life around by reducing risk behaviors and engaging in primary, secondary, or tertiary HIV prevention (e.g., becoming devoted to HIV advocacy and education after receiving a negative or positive HIV result) (Crossley, 1998; Holmes & Pace, 2002).

## ***Client Suggestions to Address HIV***

**Client Receptivity** - openness to receiving HIV program information and services (Chillag et al., 2002).

**Client awareness** - knowledge about HIV that clients bring to a program before engaging in program services (Greenberg et al., 2009).

**Client-to-personnel trust** - the belief between clients and personnel that they can discuss and understand HIV (Chillag et al., 2002).

**Client communication skills** - the ability for clients to express HIV-related needs (Rotheram-Borus et al., 2009).

## Appendix F: USF IRB Correspondence



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-5618

December 23, 2009

Peter Gamache  
College of Education

RE: **Human Research Activities Determination**  
Project Title: *HIV Education for Youth Transitioning to Adulthood*  
Date Submitted: 12-18-2009

Dear Mr. Gamache:

I have reviewed the information provided regarding the above referenced project and find the proposed research activities meet the regulatory definition of "human subject" "research" as defined by 45 CFR 46.102, 38 CFR 16.102; and/or "human subject" "clinical investigation" as defined by 21 CFR 50.3 and 21 CFR 50.1. **Therefore, an IRB Application for Initial Review must be submitted, reviewed and approved by the IRB prior to initiation of any of these activities**

**Please note that there may be requirements under the HIPAA Privacy Rule that apply to the information/data you will use in your human research activities, even if those activities do not meet the federal definitions of human subject research. For further information about any existing HIPAA requirements for this research, please contact Vinita Witanachchi, J.D., HIPAA Program Coordinator, at 813-974-5478.**

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-2036.

Sincerely,

Signature redacted

Krista Kutash, Ph.D., Chairperson  
USF Institutional Review Board

Cc: Various B. Menzel, CCRP, USF IRB Professional Staff



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-5618

February 25, 2010  
Peter Gamache, PhD Candidate  
Psychological and Social Foundations  
11322 Stratton Park Drive

RE: **Expedited Approval** for Initial Review  
IRB#: Pro00000163  
Title: Gamache Dissertation Pilot

Dear Mr. Gamache:

On 2/24/2010 the Institutional Review Board (IRB) reviewed and **APPROVED** the above referenced protocol. Please note that your approval for this study will expire on February 24, 2011.

Approved Items:  
Protocol Document(s):

Consent/Assent Document(s):

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:


(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note, the informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,

  
Signature redacted

Krista Kutash, Ph.D., Chairperson  
USF Institutional Review Board

Cc: Amanda Terry  
USF IRB Professional Staff

<a href="#">Dissertation Proposal Draft 2-8-10</a>	2/8/2010 12:58 PM	0.01
<a href="#">Informed Consent for Focus Group 2-23-10.doc.pdf</a>	2/25/2010 9:22 AM	0.01
<a href="#">Informed Consent for Interview 2-23-10.doc.pdf</a>	2/25/2010 9:22 AM	0.01



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March 25, 2010

Peter Gamache  
Psychological and Social Foundations  
11322 Stratton Park Drive

RE: **Approved Amendment Request**  
IRB#: Pro00000163  
Title: Gamache Dissertation Pilot

Dear Mr. Gamache:

On 3/24/2010 the Institutional Review Board (IRB) reviewed and approved your Amendment by full board review procedures.

Amendment Summary:

The currently approved IRB pilot study is for two (2) interviews with adult program personnel and two (2) focus groups with adults. This amendment request is to add the full "youth" component for the two pilot focus groups. The Centers for Disease Control and Prevention (CDC) uses a widely recognized range 13-24 to describe "youth" at risk for or living with HIV (e.g., CDC, 2008, 2009b, 2009c), and the Gamache Ph.D. candidate pilot study is "HIV Education for Youth Transitioning to Adulthood" that follows this range. The specifics of this amendment include: (1) expanding the focus group participants' age range 13-17 (i.e., allowing children within this range to provide assent) and (2) requesting a Waiver of Parental Consent due to the following strong rationales:

The submitted request has been approved **from date:** 3/24/2010 **to date:** 2/24/2011 for the following:

Your study qualifies for a waiver of the requirements for the informed consent process as outlined in the federal regulations at 45CFR46.116(d) which states that an IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent, or waive the requirements to obtain informed consent provided the IRB finds and documents that (1) the research involves no more than minimal risk to the subjects; (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects; (3) the research could not practicably be carried out without the waiver or alteration; and (4) whenever appropriate, the

subjects will be provided with additional pertinent information after participation.

Name	Modified	Version
<a href="#">Dissertation_Proposal_Draft_3-4-10.pdf</a>	3/4/2010 10:39 PM	0.02
Name	Modified	Version
<a href="#">Assent for Focus Group 3-22-10 (all AT comments accepted).doc.pdf</a>	3/25/2010 9:50 AM	0.01
<a href="#">Parent_Informational_Letter.doc.pdf</a>	3/25/2010 9:50 AM	0.01

This research involves children who are a protected population under Subpart D, 46CFR 46.408. As such, the Board determined that this research represents the following risk category **§46.404 Research not involving greater than minimal risk** and includes the required provisions per federal regulations: Adequate provisions are made for soliciting the assent of the children and the permission of their parents or guardians, as set forth in [§46.408](#).

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,

Signature redacted

Krista Kutash, Chairperson  
USF Institutional Review Board

Cc: Amanda Terry, USF IRB Professional Staff

### **About the Author**

Peter Gamache is a health services research and evaluation specialist pursuing a Ph.D. from the University of South Florida College of Education, Department of Psychological and Social Foundations. He also holds master's degrees in business administration, public health, and the humanities. His professional experience includes serving as the evaluator of substance abuse and HIV/AIDS outreach, testing, and treatment programs, developing educational curricula, presenting research, prevention, and policy change findings, and closely collaborating with HIV/AIDS service organizations and community-based organizations.