

**THE 'GRAYING' OF AN EPIDEMIC:  
SEXUAL SCRIPTS, PUBLIC HEALTH INFLUENCES, AND THE  
ORGANIZATIONAL IMPACT ON HIV/AIDS EDUCATION AND  
PREVENTION FOR OLDER ADULTS IN THE MIDWEST**

BY

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M.A., University of Kansas, 2001

Submitted to the graduate degree program in Sociology and the  
Faculty of the Graduate School of the University of Kansas  
In partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

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THE 'GRAYING' OF AN EPIDEMIC:  
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## ACKNOWLEDGEMENTS

First and foremost, I must thank my dissertation committee members. David J. Ekerdt, my dissertation chair, helped me refine and analyze a sometimes overwhelming amount of data riches. At times when I was frustrated and ready to give up, you were the calming voice of reason who gave me the confidence to believe that my contributions are important and have the potential to impact many people. Many thanks to Joane Nagel, for offering helpful guidance along the way, and for helping to shape me (sometimes through force!) into the scholar I am today. I am truly grateful for all that you've done for me, both professionally and personally. Thanks to Mary K. Zimmerman and Brian Donovan, whose guidance on my past work and area exams helped to discipline my writing and research abilities. Finally, special thanks to Rosemary Chapin, who not only introduced me to the world of aging, but also provided me with opportunities to stretch beyond what I thought I was capable of doing.

Among the most fulfilling aspects of researching and writing this dissertation was the opportunity to get to know some of the special people who dedicate their lives to eradicating the most destructive plague of our time. I am infinitely indebted to all of the state policymakers and AIDS service organization personnel who provided me with valuable insights and heartbreaking stories from the battlefield of the HIV/AIDS epidemic. Their compassion and dedication to this line of work is awe-inspiring and humbling. I have been blessed for having met these extraordinary men and women.

I benefited from the generous financial help provided by The Horowitz Foundation for Social Policy, and especially Irving Horowitz, whose generosity has helped many scholars to investigate pressing social issues and perhaps change policies that will have a sustained impact on our society. I also benefited greatly from the receipt of a University of Kansas Graduate School Dissertation Research Scholarship. Over the years, the Department of Sociology at the University of Kansas has been generous with research funds that helped financially support this project early on.

Finally, I am thankful for the people who supported me throughout this entire process. My family (especially my parents) and friends may not have always understood what I was doing or why I was doing it, but they have always been quick with a compliment and proud of my accomplishments. Their encouragement has been invaluable, and at times, was the only thing that kept me going.

## **ABSTRACT**

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### The 'Graying' of an Epidemic: Sexual Scripts, Public Health Influences, and the Organizational Impact on HIV/AIDS Education and Prevention for Older Adults in the Midwest

Older adults' sexual health is becoming an increasingly important component of healthy aging in the wake of the HIV/AIDS epidemic and rising infection rates among this age cohort. However, research reveals that this population is often left out of HIV/AIDS public health policy and prevention education. This project uses qualitative methodology to analyze the possible social factors for this omission. To do this, I performed 31 interviews with key personnel at HIV/AIDS service organizations and state-level policymakers in four states in the Midwest. In addition, I conducted an in-depth organizational analysis of an AIDS service organization in one Midwestern state, undertook a content analysis of key funding and policy documents, and collected U.S. national and regional data on infection rates, risk behaviors, and other contributing factors to the rise of HIV/AIDS risk and infections among the older adult population.

From the beginning of the epidemic in 1981, the seemingly disproportionate impact that HIV/AIDS had on specific segments of the population resulted in moral judgment of those who were infected. The association of HIV/AIDS with specific groups seen as being "high risk" resulted in certain segments of the population, such as older adults, being considered as low-risk for contracting the virus despite

exhibiting high-risk behaviors. The responsibility of a national public health crisis fell squarely on the shoulders of community-based AIDS service organizations who received little fiscal support. The result was gaps in prevention education to certain segments of the population.

The increase of HIV/AIDS diagnoses in the older adult population has ignited the need to understand the reasons why older adults have been omitted from HIV/AIDS policy. I examined the social forces that influence HIV/AIDS policy at the national, state, and community level. My findings reveal that HIV/AIDS policy at the national level influences the type of health promotion being done at the state and community levels. AIDS service organizations are held responsible for this national public health care crisis with too little funding. As a result, these organizations are not able to reach every at-risk group, including older adults.

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## Chapter 1: Confronting a modern plague

*Most world-historic events—great military battles, political revolutions—are self-consciously historic to the participants living through them. They act knowing that their decisions will be chronicled and dissected for decades or centuries to come. But epidemics create a kind of history from below: they can be world-changing, but the participants are almost inevitably ordinary folk, following their established routines, not thinking for a second about how their actions will be recorded for posterity. And of course, if they do recognize that they are living through a historical crisis, it's often too late—because, like it or not, the primary way that ordinary people create this distinct genre of history is by dying (Johnson 2006: 32).*

The ferocity with which the HIV/AIDS epidemic spread in the 1980s among the disenfranchised created a socially constructed moral landscape for those with HIV/AIDS. Children, hemophiliacs, and blood donor recipients were considered innocent victims, while those who contracted the virus through behavioral choices—sex, drugs, and other so-called illicit behaviors—were seen as deserving of their disease. The epidemic divided society between those who wanted to protect their own from the evil scourge of the diseased versus those who viewed it as a virus that did not discriminate. According to Glick Schiller (1992),

An age-old paradigm of the contagious cultural other both delegates the origin of the disease to the cultural other, who is seen as different and immoral, and holds that the disease is highly contagious so that the “other” must be separated from the body politic (239).

HIV/AIDS was more than a simple blood-based virus. As Richard Padgug (1989) explained, “social, political, ideological, economic, religious, and public health realities” defined the meaning associated with HIV/AIDS, as well as how those who were infected or felt the impact of the virus were treated (293).

What is perhaps most fascinating about the HIV/AIDS epidemic is that there

is nothing extraordinary about how it is spread. While some viruses, such as cholera or the flu, can move from host to host at a rapid rate, the HIV/AIDS virus is passed on from person to person through “established routines” (Johnson 2006: 32). Having sex, injecting drugs, breastfeeding a child, receiving blood products—these are potential fatal mistakes with permanent repercussions. Commonplace life practices of ordinary people had an extraordinary impact that often has caused divisions among the U.S. government, health officials, and the general public.

While epidemics in the US traditionally have been swift-moving and show physical manifestations early on in the infection period (cholera, for example, can kill within a matter of hours or a day), the HIV/AIDS epidemic differed. The virus’s potential for a long incubation period and constant mutation meant that seemingly healthy people were unknowingly infecting others for years before showing any signs of the illness. This difference alone suggested that prevention education and testing were of the utmost importance in the fight against the HIV/AIDS epidemic. However, inadequate funding has resulted in limited prevention education. Most prevention education is geared towards specific groups deemed “high risk,” while other groups, despite having increasing numbers of new HIV infections and AIDS diagnoses, are not receiving focused prevention education.

This dissertation focuses on one such group. HIV/AIDS is traditionally viewed as a younger person’s disease, but this is changing as people are living longer with the disease and becoming newly infected at older ages (Emlet 2006). Older adults who are of pre-retirement and post-retirement age are often overlooked when

addressing the issue of HIV/AIDS, as their sexual needs are generally “misunderstood, stereotyped, and ignored” (Schlesinger 1996). The proportion of older adults in all age categories over 50 with HIV/AIDS continues to rise because those who are infected are living longer due to life-sustaining medications and new infections (Neundorfer et al. 2004). However, HIV/AIDS prevention education for older adults may be lacking both at the state policy level as well as at the community level. The social forces that influence HIV/AIDS policy which states reinforce and exert on AIDS service organizations at the community level are examined. Reasons for the possible omission of older adults from prevention education campaigns due to these forces and their theoretical underpinnings are explored.

### **U.S. Epidemics**

Krieg (1992) states that few words are able to conjure such powerful and devastating images as the word *epidemic*. Epidemics historically have been blamed on various groups seen as being on the fringe of society; witches and heretics, Jews, the poor, the Irish and Italians, immigrants—all were blamed as being the origin for disease at some point in history. This propensity to blame socially stigmatized groups for the physical and societal ills resulting from an epidemic is a part of American culture (Markel & Stern 2002). In this sense the HIV/AIDS epidemic was not unique among epidemics, as Africa and its inhabitants were viewed as the reason why the epidemic existed in the first place (thought to be due to Africans’ primal sexuality and their sexual consorting with monkeys). As the epidemic continued to gain strength, gay men were thought to be the cause due to their uncontrollable and immoral sexual

appetites. This precedence of blaming a stigmatized group for an epidemic, then, means that the HIV/AIDS epidemic began in a similar fashion as other epidemics in United States history. And in some ways, the HIV/AIDS epidemic **was** like other epidemics. But the differences that set the HIV/AIDS epidemic apart from other US epidemics were far greater than the similarities. In order to better understand these differences, how epidemics are approached and managed must first be examined.

In the US, there have traditionally existed two different types of preventive medicine: private health, in which individuals are treated by medical practitioners, and public health, where groups and communities are targeted by public health officials (Coreil & Levin 1984). While an individual's everyday health problems are typically dealt with by their private physician, anything impacting whole populations—primarily epidemics—falls under the authority of public health. Public health is the idea of translating the findings of the laboratory setting into a language and activities that are accepted by the general public, who then change their potentially dangerous behaviors (Gazmararian et al. 2005; Morgan & Tyler 1971). Traditionally, public health activities have, and continue to include, health promotion (promoting healthy behaviors and lifestyles) and disease prevention (Valdiserri 2003a; World Health Organization 2000). The government is seen as being responsible for the coordination of public health for the entire population (Curran 2003).

Despite not always having had the rich financial and social backing of the medical system (Gordon 1993), public health in the US has a long tradition of

monitoring the overall health of the population especially during times of medical crises. This medical monitoring, surveillance techniques and quarantines had its roots in empirical medicine during epidemics. The medical gaze in the prison system that Foucault (1995) examined could easily have been applied to the cholera, yellow fever, flu, polio, and tuberculosis epidemics that ravaged the US during the nineteenth and twentieth centuries. Surveillance and vital statistics became the key components of the epidemiological investigation of disease and developed as a function of health departments after 1891 (Ritz, Tager & Balmes 2005; Doughty 1994; Terris 1987). Foucault's (1973) work on the medical clinic reveals that clinical observation, or viewing the body of the diseased, was the first step in producing medical knowledge. After this first step in the surveillance process, any symptom observed within the diseased body was then associated with the disease itself. Surveillance became important in defining an epidemic. Looking for common characteristics among the diseased—such as being a heretic, an immigrant, or a homosexual—became more important than looking at the virus itself.

Such was the tradition of epidemics in the US. Group association was thought to be a risk factor until it was proven otherwise. For example, cholera first emerged in poor areas that lacked sanitation and adequate housing, and therefore was thought to be a “disease of poverty” (Krieg 1992). Only when the disease entered mainstream America did public officials take it seriously enough to enact measures to fight the epidemic. Epidemical diseases sometimes became romanticized; tuberculosis, for example, was viewed as a spiritual consumption of the body that infected members of

high society.

Historically, there are precedents for treating infectious diseases in the US. The monitoring of individuals or populations who are infectious has a long record with statutes on the books giving local health officials authority to take the necessary means to prevent the spread of the disease dating back to 200 years prior to the first diagnosis of AIDS (Quam & Ford 1990). The belief in quarantine for the diseased is also a historical concept that is as old as the recognition of contagious diseases (Krieg 1992). It was not uncommon for those who fell victim to certain communicable diseases—tuberculosis, for example—to enter a sanatorium. The sanatorium movement in the US began in the late-19<sup>th</sup> century with patients entering these locations and being observed by the watchful eyes of medical personnel. There was an emphasis of shared responsibility between the patient and medical officials in the recovery process during the sanatorium movement. The push for personal responsibility for one's illness and health re-emerged during the late 1970s, perhaps helping to ignite the personal responsibility and blame associated with contracting HIV/AIDS.

It was during the late-nineteenth and early-twentieth centuries that epidemics, and really all of medicine, became enmeshed with politics and government. For example, the creation of the National Tuberculosis Association (later the American Lung Association) increased awareness, policy, and funding for the epidemic. Eventually working alongside the government, national agencies such as this would become a mainstay in American culture. By the mid-1900s, each major disease in the



US had its own national organization except polio, which actually had two organizations (Chambre 1999).

With the support of national organizations and the US government, the scientific community was able to nearly eradicate several communicable diseases in the twentieth century, seemingly ending the threat of epidemics in the US. Antibiotics swiftly stamped out tuberculosis and syphilis, and vaccines for polio and smallpox were considered some of the greatest successes of modern medical history (Hays 2005). The US government was making great strides in their surveillance techniques as well. In 1891, the Hygienic Laboratory (renamed the National Institute of Health in 1931) was organized as a focal point of the burgeoning field of epidemiologic research. During the 1930s, the use of contact tracing and partner notification stemming from the spread of venereal diseases was pioneered, a strategy that is still widely accepted today (Doughty 1994). In 1946 the Communicable Disease Center (later the Centers for Disease Control or the CDC) was founded after being converted from the Malaria Control in War Areas, and public health became a permanent fixture in the US medical system (Terris 1987). As Hays (2005) points out, biomedical medicine truly seemed to have conquered epidemic disease through surveillance of the diseased, possible quarantine of the sick, biomedical treatment of the infected, and vaccination of the uninfected. Epidemics seemed to follow this pattern through the end of the twentieth century...that is, until AIDS came along.

According to Krieg (1992), the American response to epidemics has taken three forms: (1) a panic response such as quarantine, seeking to find the source of the

disease and remove it; (2) denial, ignoring the presence of the disease; and (3) a rational or scientific response, finding the source of the disease and treating both the individual and the disease. Historically, there have been certainly been bouts of panic response during times of epidemics. The quarantine of those suffering from tuberculosis, for example, was essential so the infected did not spread the disease to other individuals. Denial was also not uncommon; cholera, for example, was thought to be a disease that only infected the poor. Once the source of contagion and modes of infection are uncovered, most epidemics were treated rationally through scientific means. Epidemical diseases in the modern world were thought to be defeated by developing a vaccine.

The HIV/AIDS epidemic did not exactly follow this pattern. After a quarter century of fighting the epidemic, there are still individuals who continue to deny that anyone but gay men, intravenous drug users (IDUs), and prostitutes can become infected. Despite the fact that the modes of transmission of the HIV virus have been communicated to the general public for some time now, Americans are still becoming infected at the same rate as they were over a decade ago. Talk of quarantining those who are infected as well as forced testing of certain populations continues to be open to discussion, and the World AIDS Conference cannot be held in the US because the government will not allow those with HIV into the country. Denial, both of the continuing danger of HIV/AIDS and personal risk factors, continues to dominate American culture. At the same time a vaccine still evades the scientific community despite early predictions that this disease would be eradicated long ago.

## **The US HIV/AIDS Epidemic**

Towards the end of the twentieth century, the focus of public health interventions shifted from individuals to groups, and risk factors that permeate the entire population were closely monitored (Frank 1997; Coreil & Levin 1984). The American health polity reached what Fox (1988) calls a “profound crisis of authority” (316) in which medical research became increasingly based on outcome measurements. Medicine as a profession became more accountable to funders and the general public.

Currently, the new focus of public health care is based on preventive services or an intervention, versus dealing with disease as it arises, which greatly revises the biomedical model (Bunton & Macdonald 2002; Frank 1997). Public health now involves investigating infectious diseases, declaring and enforcing quarantines, adopting and amending regulations concerning disease, and inspecting possible locations of disease (Quam & Ford 1990), all of which took on new importance with the AIDS epidemic.

Human Immunodeficiency Virus (HIV), the virus that causes Acquired Immune Deficiency Syndrome (AIDS), has a surprisingly long history despite being a relatively new disease in the U.S. The history of the virus is still not entirely clear, but researchers believe its origin is Africa in the 1930s, and that it entered the U.S. sometime in the 1960s (Chong 2007; The Henry J. Kaiser Family Foundation 2007k). While people certainly have been infected with the virus since its entrance into this country, the first recognizable appearance of the virus occurred in 1981, and it was

finally given a name in 1983.

HIV is transferable through bodily fluids (blood, semen, vaginal fluids, breast milk), but the virus is very delicate and can only live outside of the body for a short time. The virus can have a very long incubation period (7-10 years after infection, and in some, much longer), during which the infected individual will show no symptoms. This incubation period in which the virus lies dormant is the reason why testing is so vitally important, because an infected individual can unwittingly pass on the virus.

When an individual is in the later stages of HIV disease and has a combination of one or more infections recognized by the Centers for Disease Control (CDC) and a low t-cell count (otherwise known as a compromised immune system), they are diagnosed with AIDS. It is possible that someone is diagnosed with AIDS without ever having been diagnosed with HIV if they are in the later stages of their disease and have not been tested until these stages. The definition of AIDS underwent revisions in 1985, 1987, and 1993, which was especially important because certain groups within the population—women, for example—were not included in the original definition. Because of this omission, they were left out of clinical trials and were determined not to qualify for government benefits. Before the 1993 revision of the definition of AIDS, it was possible for someone with HIV to have certain types of often-fatal HIV-related diseases and not meet the criteria for AIDS. As a result, an increasing number of people, many of whom were minorities, did not qualify for financial benefits via government programs and were not represented in the AIDS

surveillance numbers which determined state funding (Buehler 2003).

According to The Henry J. Kaiser Family Foundation (THJKFF), the HIV/AIDS epidemic has claimed 25 million lives worldwide since 1981 and nearly 40 million individuals worldwide are currently living with HIV/AIDS (2007d; 2007e). Current predictions estimate that between 60-100 million more HIV infections will occur by 2015, and as many as 250 million HIV infections by 2025 (Behrman 2004). At least 117 million people are likely to die from AIDS-related illnesses between 2006 and 2030. However, if new HIV cases can be prevented and access to antiretroviral drugs improved, this figure could be reduced to 89 million (THJKFF 2006e). Even with the best case scenario, AIDS-related illnesses are likely to become the third leading cause of death behind heart disease and stroke within the next 25 years (THJKFF 2006e).

In the U.S., 1.7 million people have been infected with HIV/AIDS, including 550,000 individuals who have died (THJKFF 2006h; THJKFF 2005d). While the incidence rate of HIV has decreased considerably since the 1980s when it peaked at over 150,000-160,000 new infections per year, the number of new infections has remained steady at 40,000 a year for the last fifteen years with predictions of increases in certain populations (heterosexuals and older adults, for example) (THJKFF 2006h; THJKFF 2006f; Holtgrave 2003). For example, while men who have sex with men (MSM) has traditionally been the most affected group in the U.S., the percent of all new infections per year among MSMs fell from 65% to 43% from 1985 to 2005. During the same period of time, intravenous drug users (IDUs) rose

from 19% in 1985 to 31% of all new infections per year in 1993 before dropping to 20% in 2005. Perhaps mimicking the global epidemic trend in which heterosexual transmission is the number one mode of transmitting the virus, heterosexual transmission in the U.S. increased from a mere 3% in 1985 to 31% per year in 2005 (THJFF 2006h; THJKFF 2007e).

Not only is heterosexual transmission increasing at a faster rate than new infections due to “traditional” risk activities (MSM, IDUs), but the centers of the HIV/AIDS epidemic in the U.S.—the large metropolitan areas and the East and West Coasts—are beginning to shift a bit to include the South and Midwest. The 2005 annual AIDS case rate (new diagnoses) per 100,000 in the U.S. was 25.6 for males and 8.6 for females (THJKFF 2006i). Additionally, the estimated prevalence rate per 100,000 living with HIV or AIDS was 136.5 for HIV and 176.2 for AIDS (CDC 2005).

Regionally, the prevalence rate of HIV infection per 100,000 individuals is still highest in the Northeast at 22.2, which is to be expected with New York being the city with the largest number of people infected with HIV/AIDS. When looking at the prevalence rate of AIDS, the District of Columbia by far had the largest rate of AIDS cases in 2005 at 128.4 people per 100,000. In comparison to the District of Columbia, the state of New York had an AIDS case rate in 2005 of 32.7, followed by Maryland (28.5) and Florida (27.9) (THJKFF 2007e). However, the South is quickly approaching this rate of infection at 18.4. Further, the South has the greatest number of people newly diagnosed with AIDS, the estimated number of people living with

AIDS, and AIDS deaths. Perhaps giving even more strength to the argument that HIV/AIDS is no longer just a problem of the East and West coasts, between 2001 and 2005, the number and percent of AIDS cases increased the fastest in the Midwest at 38%, followed by the South at 19% (THJKFF 2006h).

Minorities have been, and continue to be, disproportionately affected by the U.S. HIV/AIDS epidemic (THJKFF 2005d). In 2005 they represented 71% of new AIDS cases and 64% of all people living with AIDS (THJKFF 2007e). In fact, data from a national household survey found that more than 2% of all Blacks ages 18-49 in the U.S. were HIV positive (McQuillan et al. 2006). In addition, there are increasing proportions of women with AIDS, a trend that dispels the myth that this is a gay man's disease (Karon et al. 2001). The percent of new AIDS diagnoses who are women has risen from 8% in 1985 to 27% in 2005, with Black women being most at risk for new diagnoses. In 2005 alone, Black women made up two-thirds of all new diagnoses among women (THJKFF 2007e).

Perhaps the most disturbing fact is that, due to low testing numbers, approximately 24-27% of those who are infected do not even know they are HIV positive (THJKFF 2005d; THJKFF 2007e). With epidemiological studies showing an increase in HIV-related risk behaviors in some communities (Holtgrave & Pinkerton 2003), this is an especially dangerous trend. Not only are they at risk of transmitting HIV to others, but are also not taking advantage of early medical interventions that could prolong their healthy life, which could lead to more related illnesses and higher medical costs (Chesney & Smith 1999).

## **HIV/AIDS: A “Different” Epidemic**

The AIDS epidemic has proven to be what Fauci (1999: 1048) describes as “one of the most destructive microbial scourges in history,” yet the beginning of the AIDS epidemic seemed not unlike other infectious diseases. Several men in certain areas of the country were coming down with infections that decimated their immune systems. As more cases emerged in other cities, it appeared that a new epidemic was on the horizon. Emergency measures such as surveillance, research, prevention, and treatment should have been coordinated through federal and state governments, which was the same protocol used to control epidemics as recent as the 1970s— Legionnaires’ disease and toxic-shock syndrome (Donovan 1997; Fox 1988).

But the beginning of the AIDS epidemic was also full of contradictions. The country was dealing with a burgeoning and misunderstood epidemic that was ravaging whole communities, and yet the US government wanted to contain health costs and was reluctant to accept any responsibility for the devastation caused by the new epidemic (Altman 1994). The prediction of a great swine flu epidemic in the 1970s turned out to be a disastrous and costly calculation (Lune 2007; Hays 2005; Krieg 1992). The government had spent much time, effort, and financial resources to develop a program to resist the impending epidemic that never actually surfaced, and therefore were leery of establishing government programs for a new disease seen among a few gay men.

In addition, the marginalization of those infected with HIV/AIDS caused a delayed response to the epidemic that endangered public health (Thomas & Quinn



1993). Little funding or governmental involvement was allocated to the impending medical crisis during the 1980s. Perhaps due to the fact that AIDS was associated with homosexuality and drug use, officials and policymakers often refused to address the epidemic. President Ronald Reagan did not utter a single word concerning the epidemic during its first 6 years; one of his first comments in response to the epidemic was in 1987 when he said “Maybe the Lord brought down this plague” (Behrman 2004). Political leaders only discussed the epidemic when it was related to “innocent” victims—babies who contracted the disease in-utero, or people who received tainted blood transfusions. The repercussions of these actions were especially evident in how the general public viewed their own risk for HIV. If the government was not worried about this disease that seemed to only kill gay men, drug users, Haitians and hemophiliacs, why should anyone else worry about their own risk?

Along with the governments’ (lack of) response, the mass media virtually ignored the outbreak of the new disease during its early years. Valdiserri (2003b) points out that the 1976 outbreak of Legionnaires’ disease, a small and contained outbreak, garnered more media coverage in a short amount of time than AIDS did in its first two years of “existence.” When the first news report was published, its title—“The Gay Plague”—not only set into motion the stigmatization of a sub-group of the population, but also set a precedent that AIDS was a strictly gay disease, leaving most of the U.S. feeling as though they were far removed from being at risk.

Krieg (1992) reminds us that one of the ways that the US has handled

epidemics in the past is to ignore them. In this sense, the early years of the HIV/AIDS epidemic were similar to that of other epidemics. The spread of the epidemic was blamed on groups of disenfranchised individuals and thought to be contained to those groups. But how does the epidemic differ from other diseases and past epidemics? Several main components of the epidemic seem to stand out. First, a quarter of a century after it was recognized by the scientific community, HIV/AIDS has no cure, no effective vaccine, and spotty treatments that may or may not work to alleviate the symptoms of the disease. Second, unlike other epidemics, HIV has a very long incubation period which could be void of symptoms, leaving the door open for an infected person who does not know their status to infect other unsuspecting individuals. Further, most individuals underestimate their risk for infection, and subsequently there are low testing numbers in most populations (THJKFF 2007d). With roughly 25% of the US HIV-positive population and 80% of the global HIV-positive population not knowing their status (THJKFF 2007d), testing is of vital importance.

Third, and arguably the most important difference, HIV/AIDS has a significant and persistent stigma that remains to this day. According to Herek (1999), AIDS stigma is particularly destructive because it is more attached to a disease which is thought to be a result of the bearer's behavior. Personal responsibility is the focus of much HIV/AIDS preventive policy (i.e., "protect yourself, get tested"), further stigmatizing those who test positive for not taking the proper protective precautions (Kaufman 1998). In their research on the level of stigma associated with certain

diseases, Fernandes et al. (2007) found that AIDS had the highest level of stigma than any other disease, and that having AIDS somehow implies that an individual is being punished for personal irresponsibility or immoral behavior. As a public health expert once commented, diseases associated with sex “came to be seen as an affliction of those who willfully violated the moral code, a punishment for sexual irresponsibility” (Behrman 2004: 25).

The stigma associated with being constructed as “the other” can have both individual and group effects (Goffman 1963; Parsons & Atkinson 1992). When it came to the AIDS epidemic, associating the virus with particular groups resulted in using stigmatized stereotypes as categorical devices, resulting in prejudice and discrimination against people who were *perceived* to have HIV/AIDS, even if by group association only (Fernandes et al. 2007; Herek 1999; Prohaska et al. 1990). HIV/AIDS stigma and discrimination continue to be pervasive, and could have an impact on whether or not an individual will get tested for HIV. For example, while HIV-positive individuals or people with AIDS were once worried about losing their job or having their homes burned down, now insurance companies are dropping the policies of people who test positive. Additionally, the threat of using restrictive measures to quarantine (or even brand) infected individuals has long been under consideration by public officials in the U.S. and abroad (Misztal & Moss 1990; Musto 1986).

Fourth, this epidemic is different than previous epidemics in U.S. history because illness has the potential to linger on for years before death, resulting in

extreme financial costs. Given the fact that the AIDS epidemic is a young epidemic and there is no cure or vaccine, the number of infections and deaths, as well as the cost to society, are staggering. As the lifetime costs of treating HIV/AIDS continues to rise—from \$119,300 in 1993 to \$618,900 in 2004—the importance of funding is not diminishing (Schackman et al. 2006). Further, the rising costs of medical care for people with HIV or AIDS has caused many private insurers to impose cost caps or even drop the insurance of someone who is sick (Schackman et al. 2006).

The social cost and degree of suffering is also high with HIV/AIDS, and the disability-adjusted life-years of this particular disease—the age of the infected, the degree of disability, and the number of deaths—all have had the highest health-care costs and loss of productivity to society of any disease in modern history. HIV/AIDS remains the only disease in which states and institutions are receiving grants and reimbursements to help coordinate both inpatient services and services in the community, with only end-state renal disease being comparable with its disease-specific case management (Fox 1988). These grants and reimbursements are necessary as HIV/AIDS is a disease that has the potential to linger for several years, thereby costing more than other diseases. Due to the expense associated with HIV/AIDS drugs and treatments, federal funds are unable to cover all related expenses.

Fifth, this epidemic has forced the U.S. to balance the needs of society (protecting them against an epidemic) versus protecting individual rights (protecting the rights of those who are infected). During the 1980s, there was a strong movement

by AIDS advocates towards keeping confidential the names of those who were infected with the virus, especially because of the stigma and discrimination surrounding the disease. Privacy in testing was actually intended to promote public health goals by encouraging those who exhibited high-risk behaviors to be tested and seek medical attention in the first place (Doughty 1994). However, the increasing public health involvement in the epidemic and case surveillance has forced states to adopt confidential name-based HIV reporting as a requirement for receiving federal funding (THJKFF 2007c; THJKFF 2006c). This debate over confidentiality is at the heart of the AIDS policy debates in which the government must reconcile trading in personal freedom for the good of society (Gostin 2006; Doughty 1994; Peck & Bezold 1992).

Finally, this epidemic differs from previous epidemics because there is no national central agency devoted solely to the treatment and prevention of HIV/AIDS exists. During past epidemics, tuberculosis and malaria for example, national organizations were established that would work in tandem with the government to eradicate the disease. This tradition continues today with agencies such as the American Cancer Society and American Diabetes Association. Freeman and Robbins (1994: 270) believe that protecting the public's health depends on "national investment and coordination," as is evidenced by the power these agencies have in fighting diseases when receiving governmental support.

Unlike other diseases, HIV/AIDS does not have a national organization, and there continues to be a lack of uniformity across states in their programs and services.

The lack of a comprehensive national AIDS plan or strategy—a requirement that the U.S. has of other nations who receive U.S. dollars for AIDS—is a detriment to both prevention and treatment. It is also cost-prohibitive and a drain on funding sources because there are agencies that are providing the same services within the same community, and all are receiving some level of funding. If these agencies were combined to provide specialized services through the effort of a comprehensive national AIDS plan, it would ultimately save money and more services could be provided. This has become a cause that many hope will be addressed by the new administration in 2008, as more than 100 organizations (including the Sociologists AIDS Network) have signed a petition calling for a national AIDS strategy (National AIDS Strategy 2007).

According to Doughty (1994), “HIV remains a politically as well as epidemiologically volatile disease” (136). But how did it get to such a place of volatility? The answer lies in the fact that the HIV/AIDS epidemic in the U.S. has been socially constructed, involving the interweaving of complex social interactions among different social, political and historical entities over time (Padgug 1989). This was a trend that began with the U.S. government and the CDC at the beginning of the epidemic in which the U.S. population was divided into two different sectors: the general population, who were at risk through a specific act, and “risk groups” who had risk embedded in their identity (Glick Schiller 1992). This construction of risk groups, according to Devine, Plant and Harrison (1999: 1212), became a lasting and dangerous pattern that still exists to this day.

The public's focus on risk groups may be the single most destructive social component of the AIDS epidemic. Even AIDS education materials have promoted a rather prevalent us versus them theme. Members of the risk groups and PWAs [Persons with AIDS] had become a menace to the health and social identities of the general public.

Placing blame for infection on *groups* rather than *individuals* who exhibit risk behaviors was what Kuller and Kingsley (1986) call a failure of public health policy. The historically familiar response to disease—placing blame—was set into motion with the discovery of HIV/AIDS (Donovan 1997). According to Donovan (1997), by defining and categorizing HIV/AIDS as an STD, despite the fact that HIV can be contracted in non-sexual ways, prevention and treatment were bound to involve policy debates that involved moral judgment.

### **A New Social Movement**

Despite the destructiveness of the epidemic and evidence that prevention programs can be an integral part of slowing the path of the epidemic, government agencies continue to favor “the study of illness more than health, treatment more than prevention, and biomedical more than behavioral approaches” (Peck & Bezold 1992: 132). By the late 1980s, it became clear that the government could not ignore the growing need for funds dedicated to bio-medical research on the epidemic and clinical studies on potential vaccines and pharmaceuticals to treat HIV and AIDS-related illnesses. By and large, the push for funding for the HIV/AIDS epidemic and clinical drug trials came from the gay community, who were the heart of the AIDS social movement in the 1980s. Responsibility for the epidemic fell—for right or for wrong—on the shoulders of the gay community. The new public health movement of

the late 1970s and early 1980s laid the groundwork for what could be the most unique feature of the HIV/AIDS epidemic in the U.S.: the rise of community organizing and the AIDS social movement, both of which undoubtedly changed the course of the epidemic and public health in the U.S. in a fashion that was “remarkable and nearly unprecedented” (Lune 2007: 4).

While the government virtually ignored the burgeoning epidemic during its early years, the gay community took it upon themselves to become activists. According to Altman (1999; 1988) and Gamson (1989), the gay community is the only group among those most affected by AIDS that has been able to mobilize and articulate political demands. The activist community was generally made up of white, middle-class men who had an adequate amount of political clout and fund-raising capacity, and they were seeing their friends die while the country stood by and did very little to help. Their protests generated attention and controversy, and caught the attention of key leaders, medical officials, and pharmaceutical companies. Drug trials, medical advances in HIV/AIDS research, and increased funding can all be considered as byproducts of this community activism. If no one else was going to help the gay community fight this plague, they were going to do it themselves by becoming HIV/AIDS activist-experts (Epstein 1995). Epstein (1996) points out another unique feature of the AIDS epidemic, in which the gay community at times surpassed the medical community with their knowledge about the epidemic.

The AIDS movement can best be compared with the relatively short list of movements that neither simply enlist experts nor attack them but, rather, undergo the process of “expertification.” A participant in such a movement learns the relevant knowledge base so as to become a sort of expert; more



broadly, such participants transform the very mechanisms by which expertise is socially constructed and recognized (13).

An especially important and groundbreaking result of gay activism during the 1980s was the establishment of AIDS service organizations, or ASOs. ASOs were a direct response to what Shamblee (2001: 229) refers to as the “lack of humane treatment and denial of basic medical services.” Alperin and Richie (1989: 166) stated early on that ASOs are the “cornerstones of the community’s response to the epidemic.” They are grassroots community-based organizations that were founded in the 1980s by gay men who decided to start organizations that would deal with taking care of their dying friends’ emergency needs (Lune 2007; Shamblee 2001; Siplon 1999; Gabard 1995; Wilson 1995). In addition, ASOs were founded to help prevent discrimination faced by many infected individuals at the hands of the medical community, their workplaces, and home environments. As Mor, Fleishman, Allen and Piette (1994: 93) state, ASOs are “social movement organizations, concrete manifestations of the response of the Gay Rights movement to the crisis of the AIDS epidemic.”

ASOs provide counseling and testing services, case management services for HIV positive people or persons with AIDS (PWAs), and prevention education in the community in which they are located. In essence, ASOs provide direct services, palliative care, and prevention education to a wide range of different populations (Barton-Villagrana, Bedney & Miller 2002). If a person wants to know about HIV/AIDS policy, how it affects people with HIV/AIDS, how prevention education works, how to find services for people with HIV/AIDS, and anything else even

remotely connected to the epidemic, ASOs are where one should look for answers in the absence of a national HIV/AIDS organization. As Quam and Ford (1990: 42) state, “What have these organizations actually done? One is tempted to answer, everything.”

ASOs—which are incorporated as 501 (c)(3) non-profits—act as independent entities in most ways except that they have to follow certain rules and regulations if they accept federal money, most notably Ryan White Care Act funds for people with HIV/AIDS. During the early years of the epidemic, ASOs were supported almost exclusively by wealthy gay donors and volunteers (Chambre 1999; Levitt & Rosenthal 1999). Now they rely on donated resources, such as government grants, foundation monies, and fundraising efforts, and are overwhelmingly staffed by volunteers. As federal money for HIV/AIDS continues to be directed away from direct services and prevention, ASOs are relying heavily on fund-raising skills and diversifying their funding portfolios. However, the once important cause of HIV/AIDS that was so popular during the late 1980s and early 1990s has been replaced by a focus on breast cancer, autism, and other perhaps less stigmatized diseases. Further, the tradition of having volunteers run the organizations has shifted since the early days. Many gay men who once ran the organizations have either died of AIDS themselves or have relinquished control of the organizations to underpaid staff due to what Vargas (2006) believes is the gay community experiencing AIDS fatigue.

The ASO as an organization has had to shift its focus as people are living

longer with HIV/AIDS. When they first emerged, ASOs were seen as temporary emergency responses that would fold after the epidemic had passed or a vaccine was found. Now that infected individuals are able to fend off late-stage infections thanks to newer AIDS drugs, people with HIV/AIDS require case management services for years rather than months. While this is certainly good news that people are living longer with HIV/AIDS, there is the problem of a diminished urgency associated with the epidemic (Lewis & Crook 2001). This is especially dangerous as it has diverted attention and resources away from the epidemic. The fact is that there is an increase in service use and service users which has resulted in higher demands for ASOs on limited resources (Dodd & Meezan 2003; Cain 1997).

Despite the fact that their client level has increased, funding has not kept up with demand levels. Many ASOs receive the same, if not less funding than they did several years ago. While funding for HIV/AIDS abroad has become an increasingly important cause celeb for the U.S. (and rightfully so, as AIDS has been especially destructive to Africa), domestic funding for HIV/AIDS is still not adequate enough to reduce new infections. Due to the fiscal constraints most ASOs face in dealing with a public health crisis on shrinking budgets, many groups who were and continue to be at risk for HIV infection have been left out of prevention and education campaigns aimed at reducing HIV infections.

Complicating the situation even further, the HIV/AIDS epidemic was established early on by the Centers for Disease Control (CDC) as a disease that only affected specific groups who were seen as being “high risk” merely by group

membership versus behavior (Devine, Plant & Harrison 1999). This dangerous pattern has resulted in many segments of the population being left out of prevention education campaigns and subsequently do not see themselves as being at risk for HIV infection. For example, Herek and Capitanio (1999) found that, despite the changing epidemiology of HIV, most heterosexual adults continue to associate AIDS with homosexuality, despite the fact that heterosexual sex is now increasingly seen as a risk behavior (THJFF 2006h; THJKFF 2007e). This detachment from the belief that everyone is at risk can be seen as a failure of prevention education among the general public.

Using prevention education as a way to control HIV/AIDS is not a new concept. From the beginning of the epidemic, researchers were calling for more education on how the virus was spread and what people could do to protect themselves from infection. Theoretically, risk reduction involves the adoption of new behaviors by a community, changing the social norms as a whole (Pinkerton, Kahn & Holtgrave 2002). Now thanks to the Internet, scientific research is more accessible and has a huge potential for risk reduction and prevention (World Health Organization 2002). This is particularly evident with HIV/AIDS; go to any computer and type in “HIV/AIDS” and one will learn about how the virus is transmitted, who is at risk, how to protect oneself from risk, and locations of testing sites.

But the information on the Internet is not translating into a large-scale change in risk behaviors or more people being educated about the disease. According to a 2006 survey, nearly 40% of people in the U.S. think that HIV is not spread through

kissing, and 25% do not know that it is not spread by sharing a glass with someone who is infected (THJKFF 2006f). What is particularly concerning about this finding is that both percentages are approximately the same as they were in a survey from 1990. Further, one in six people in the U.S. still believes that HIV can be transmitted through toilet seats (THJKFF 2006f). How is it that sixteen years of new understanding of the epidemic results in the same level of misinformation and a lack of prevention education? The answer seems to lie within the fact that HIV/AIDS prevention continues to be overlooked as perhaps the most important element in the fight against the epidemic.

The rising cost of treating HIV/AIDS and inadequate funding create a situation in which prevention becomes an even more important concept. When it comes to federal funding for prevention, however, there has been a historical precedent of focusing governmental funds on biomedical research, which has received the highest level of funding and experienced the most consistent growth in funding since the early years of the epidemic (Levi 2003). As O'Leary, Holtgrave, Wright-DeAquero and Malow (2003) explain, this lack of public financial backing of prevention education programs actually impedes progress in the fight to slow the HIV/AIDS infection rate, as insufficient financial support results in reduced training for prevention educators. Without funding for prevention services, many groups at risk for infection are not receiving prevention education services. As history reveals, if people are not told they are at risk for contracting HIV/AIDS, they do not change their risk behaviors.

## **Who Is Left Out?**

One group in particular that does not perceive itself as being at risk is the older adult population (Orel, Wright & Wagner 2004). Several researchers (Gott & Hinchliff 2003; Herron & Herron 1999) have defined “older people” as those who are over the age of 50. Neundorfer et al. (2004) point out that the over-50 population is defined as “older adults” within HIV/AIDS demographics as well as by the National Institute on Aging and the CDC. This is certainly not the ideal approach to studying HIV/AIDS age trends, because there are likely large behavioral and risk differences between those who are in their 50s versus those who are in their 70s. It also highlights the fact that there are ageist assumptions about what is considered to be “older” in our culture. However, in order to use CDC data and stay consistent with comparisons, this study defines “older adults” as being in the 50 and over age category. Some of this research will also include the 45-49 age group when appropriate, or when that age group is grouped in with the 50+ population in state trends or numbers from the CDC.

Once a seemingly taboo subject, the topic of older adults’ sexual health is becoming an increasingly important component of healthy aging. The advent of the HIV/AIDS epidemic and rising infection rates among this age cohort have brought attention to what otherwise would have been an unmentionable subject for many older adults. Though perhaps society does not want to believe it, the longest span of sexual activity for most people will be during their middle and later years, putting them at an increased risk for HIV infection. Yet research and literature on the topic

of older adult sexual health has been limited (Herron & Herron 1999).

While popular culture may see sexuality and old age as incompatible (Gott, Hinchliff & Galena 2004) with older adults presumed to be sexless (Davidson & Fennell 2002), the rates of HIV infection and AIDS among older adults reveal that this group is indeed still sexually active. In fact, older adults were widely reported to have made up between an estimated 10-15% of the overall U.S. AIDS population alone during the early years of the epidemic. Recent studies show that this percentage has actually increased as the epidemic continued to spread beyond the initial infected groups. Keigher, Stevens and Plach (2004) found that the proportion of all AIDS cases among the 50+ population was 18.9% by the end of 2000. Recent work by Karpiak, Shippy and Cantor's (2006) reveals that 27% of all people living with AIDS in the U.S. are over the age of 50; as they state,

This pattern is seen throughout the US. Yet few have internalized this fact: there will soon be large numbers of senior citizens living with HIV and AIDS (1).

This increase is already emerging in several large cities, with older adults over the age of 50 comprising 30% of all HIV/AIDS cases in New York City, 25% of all HIV/AIDS cases in Los Angeles (Emlet 2006), and 25% of all HIV/AIDS cases in Miami-Dade (Ferri 2005). These percentages are expected to increase substantially within the next few years due to rising numbers of new HIV infections among this age group and the aging of baby boomers who are already infected (Neundorfer et al. 2004; Avis & Smith 1998; Siegel, Raveis & Karus 1998). In fact, some of these expectations are currently coming to fruition. Trends from 2001 to 2005 reveal that

HIV/AIDS cases in the U.S. increased in all age groups over 45 (CDC 2005). The estimated number of older adults over the age of 50 who are infected has increased from 59,649 in 2000 to 112,447 in 2004 (Emlet 2006). Orel, Wright and Wagner (2004) found that there was a staggering 107% increase of new HIV infections among older adults between the years of 1998 and 2002. What is even more disturbing is that the numbers might even be higher, as many older adults are undiagnosed due to low levels of testing and misdiagnoses.

The misconception that older adults do not need HIV/AIDS education because they do not participate in practices that would put them at risk (i.e., unprotected sex with an infected partner, IV drug use, etc.) has been proven false in recent years (Lindau et al. 2007). In fact, more cases of AIDS have been diagnosed in this particular population than in younger adults (Emlet & Farkas 2001). From 1991 to 1996, the proportionate increase in the number of AIDS-related illnesses was greater among older adults over 50 (22%) versus persons between the ages of 13-49 (9%) nationally (Avis & Smith 1998: 822). As the numbers and percentages illustrate, HIV/AIDS is not solely a young person's epidemic, emphasizing the importance and need for prevention education in the area of HIV/AIDS for older adults.

According to Genke (2000:198) a system of "enforced ignorance" has been a factor in the consistent rate of HIV infection among older adults since the early days of the epidemic. Research reveals that older adults have been, and continue to be universally excluded from educational campaigns (Falvo & Norman 2004; Stombeck & Levy 1998). Prevention efforts for older adults ultimately are hindered by a lack of



public awareness of AIDS rates, transmission routes, and risk factors (Ory & Mack 1998). This population lacks accurate information about HIV/AIDS at the same time as they are in desperate need of HIV/AIDS education (Altschuler, Katz & Tynan 2004). Prevention and education is particularly important since older adults are less likely to use condoms and less likely to be tested than any other age group (Orel, Wright & Wagner 2004). Additionally, some studies suggest the use of Viagra and other sexual enhancement drugs has increased the HIV risk among older adults (Gott, Hinchliff & Galena 2004; Marshall & Katz 2002).

As recently as 2001, older adults were identified by an AIDS group that tracks infection patterns as an “emerging special needs population” due to the increase in new infections (ACRIA 2004). However, this finding has not resulted in the CDC recognizing this population as being in need of prevention education. Even as the face of the U.S. epidemic is changing—and aging—older adults are rarely mentioned as a risk group.

Possible implications of a lack of HIV/AIDS prevention education for older adults include greater rates of new infections and greater fiscal cost to states (including higher Medicare and Medicaid expenses) to treat the older adult HIV/AIDS population. The estimated lifetime cost of treating HIV/AIDS continues to increase substantially. Schackman et al. (2006) found that the lifetime cost of treating HIV/AIDS increased from \$119,300 for 6.8 years of treatment in 1993 to \$274,800 for 10.8 years of treatment in 1997. As mentioned earlier, as of 2004, the estimated cost of treatment was \$618,900. This age group already utilizes medical

services more than other age groups within the US population for medical issues related to aging (Keigher, Stevens & Plach 2004). Adding in the cost of treating HIV infection or AIDS could pose a financial challenge for Medicare and Medicaid programs. Therefore, it is fiscally important to prevent as many new infections as possible, or the US will face the task of having to provide costly long-term HIV/AIDS care for increasing numbers of citizens.

### **Scope of Dissertation**

Many sociologists have studied HIV/AIDS. However, the literature is not nearly as diverse in the area of HIV/AIDS and aging as other topics—HIV/AIDS and race, class, gender, or sexual orientation, for example. Much of the recent work in the area of HIV/AIDS is done on an international scale, looking at the epidemic and its affect on other nations. Further, despite being the region with the largest percent of new AIDS diagnoses between 2001 and 2005, the Midwest is certainly not a focus in much research. Preston et al. (2002) points out that it is critical to focus on rural areas such as those located in the Midwest, because there is an increase in the number of individuals with HIV/AIDS and restricted care available for those who are infected. Also, rural service providers rely on ASOs for prevention, education, and case management services for those who are infected more than in urban areas (Roeder 2002).

My dissertation addressed the increasing HIV/AIDS crisis among older adults by uncovering the social organizational reasons why older adults in the Midwest are potentially left out of HIV/AIDS prevention and education campaigns. Using a

qualitative approach, I investigated HIV/AIDS prevention and education policies both at the state level and at the community level using multiple methods. I interviewed 13 state policymakers and 18 ASO personnel in four Midwestern states, conducted an organizational ethnography of an ASO, attended consortia meetings in the four Midwestern states, and conducted a search of public health sources (both primary and secondary). I am particularly interested in the level of older adults' inclusion in prevention education and outreach. Are older adults being excluded from HIV/AIDS prevention education? If older adults are, in fact, absent from HIV/AIDS prevention education policy, why are they absent? Is it that policymakers and health educators do not think older adults' exhibit enough risk behaviors for HIV? Is it a lack of public health funds? In other words, how do sexual scripts shape behaviors in older adults and HIV/AIDS education and outreach by public health policymakers? How do social factors influence HIV/AIDS prevention education services targeted towards older adults?

The HIV/AIDS epidemic in the U.S. has been turned into a bureaucratic problem instead of a purely health-related problem, and social constructs only complicate the situation. While the number of new infections and diagnoses among older adults of both pre-retirement and post-retirement age has grown at a substantial rate, higher than among younger adults, they are potentially absent from HIV/AIDS prevention education efforts. Chapter 2 of this research begins this exploration of the roots of the problem of HIV/AIDS among older adults. I examine the literature for possible reasons why older adults are a growing population at risk for HIV infection

and AIDS diagnoses. I then explore possible theoretical explanations for why older adults are viewed as not being at risk for infection, even though the numbers of new infections and new diagnoses are increasing. These theoretical explanations include sexual scripts and sociology of risk.

Chapter 3 explains my methodology and procedures for collecting data. I then begin to examine whether or not older adults are included in state policies, and whether they are a focus of any prevention at the state and local levels in the four Midwestern states. Chapter 4 is an examination of the organizational structure of the HIV/AIDS epidemic in the Midwest. Chapter 5 includes findings from the different methodologies I incorporated into this study, while Chapter 6 is an analysis and discussion of the data and findings from the interviews and Organizational ethnography.

Finally, Chapter 7 will focus on the ever-changing status of ASOs in light of the current political and economic climate, and how older adults will be affected by these changes. I end this dissertation with an explanation of the current and future impact that the increasing rate of HIV/AIDS infection among older adults will have on the U.S., especially the fiscal cost of providing long-term HIV/AIDS care.

## **Chapter 2: A new sexual frontier: Older adults at risk in the time of HIV/AIDS**

The social regulation of bodies has a long history in which the monitoring of the performances of bodies is relegated to the medical expert, who uses his/her “gaze” in order to judge efficiency and define bodily faults. The techniques of subjection and methods of exploitation that comprised Foucault’s power/knowledge theory of social control have been prominent forces in new developments in science, policy, technology, and medical knowledge since the 17<sup>th</sup> century (Staples 1997; Foucault 1995; Kaplan 1990). A kinder, gentler form of social control emerged in the 20<sup>th</sup> century that was less blatantly coercive and involved more anticipatory actions and general surveillance (Alford 2000; Staples 1997; Foucault 1995; Staples 1994; Kaplan 1990). In particular, the surveillance of the body, or the hierarchical observation and normalizing judgment that brands the body according to a scale of acceptability, took on greater importance.

The regulation of the body and behaviors became intertwined with issues of morality and deviancy, as people were seen as being personally responsible for bodily faults, such as disease (Foucault 1990; Turner 1984). Lifestyle choices and personal responsibility became important indicators of illness and disease, and the labeling of “deviants” and other stigmatized groups soon followed (Shildrick 1997; Wald 1997; Zola 1997; Conrad 1996; Staples 1994; Foucault 1990; Kaplan 1990). In the U.S., the HIV/AIDS epidemic has been one such example of the regulation of bodies and behaviors. During the 1980s—and, unfortunately, continuing on to the present era—

HIV/AIDS was viewed as a disease in which a person's bodily desires and low levels of morality were contributors to contracting the virus (Turner 1991). As a result of the epidemic, sexuality, desire, and physical pleasure had to be disciplined, and what were considered to be appropriate forms of sexuality and sexual expression took on even more importance as cultural guides for behavior.

The surveillance and monitoring of the human body is no longer simply a product of the panoptical prison that Foucault described; it has become a prevalent and important part within public health, such as through the deciphering of risk levels, risk groups, and risk behaviors. Without question, the HIV/AIDS epidemic has changed the public health landscape of the United States. While mimicking previous epidemics in some ways, this epidemic has also deviated from the norm and has baffled scientists and researchers alike for three decades. As McNeil Jr. (2007: 2), who commented on how AIDS has defied the "normal" epidemic paradigm, points out,

AIDS has always been maddening. It moves more slowly than anything that rides sneezes or coughs or rats or mosquitoes. It permits years of symptom-free infectivity and kills, like a torturer, at its leisure.

The manner in which the U.S. government and public health authorities approached this epidemic also defied the norm. Focusing on groups that they thought were most at-risk for contracting the disease by virtue of group membership versus behaviors has been a unique characteristic of this epidemic, arguably due to the stigma attached to HIV/AIDS. This, as I mentioned before, resulted in many groups being left out of prevention education efforts. I am focusing on one such group, older

adults. But the question remains: are older adults even at risk for contracting HIV/AIDS?

In this chapter I first examine the numbers of HIV infections and AIDS diagnoses among older adults in the U.S. Using data obtained from the Centers for Disease Control and Prevention (CDC 1990, 1995, 2000, 2004, 2005a), I look at the prevalence rate of AIDS among older adults, the age at diagnosis for AIDS and HIV, the age at death from the epidemic, and the number of older adults living with HIV and AIDS. Additionally, I use US Census Bureau data to calculate incidence and prevalence rates for HIV and AIDS among different time periods, as well as a comparison of general population increases, HIV and AIDS incidence rates, and HIV and AIDS prevalence rates. Next, I examine the literature on older adults and sexual activity in order to understand what behaviors may be putting older adults at risk for infection. I then explore the literature to ascertain whether or not public health efforts to combat HIV/AIDS through prevention education have reached older adults. I propose two possible reasons why older adults show increasing numbers of HIV infections: the introduction of erectile dysfunction medications, and the reluctance of physicians to discuss HIV/AIDS and/or sex with their older adult patients. Finally, I examine the theoretical frameworks from which my research emerged, sexual script theory and the sociology of risk.

### **Are Older Adults Even At Risk for HIV/AIDS?**

According to a study released in 2006 by the AIDS Community Research Initiative of America (ACRIA), the fastest-growing segment of the HIV population

consists of people over 50. While this may be a surprise to some, medical experts tend to agree that older adults are among the most overlooked and vulnerable populations facing the HIV/AIDS epidemic (Huffstutter 2007). The numbers and percents of new HIV infections and AIDS diagnoses in Tables 2.1 to 2.12 below (based on the CDC Annual Series and US Census Bureau data) indicate that HIV/AIDS is increasingly becoming a disease of older adults. The AIDS prevalence rate among older adults is an indication of this trend. The rate of older adults living with AIDS per 100,000 people has increased substantially from 1994 to 2000 in all age groups above 45, as is shown in Table 2.1.

**Table 2.1: Estimated rates of population living with AIDS per 100,000 by age, 1994-2000**

<b>Age Category</b>	<b>1994</b>	<b>1995</b>	<b>1996</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>
<b>45-49</b>	126.6	143.6	163.2	197.0	224.0	252.2	275.2
<b>50-54</b>	77.1	86.3	103.7	119.5	142.4	162.4	184.0
<b>55-59</b>	44.7	51.5	60.7	73.5	85.2	99.4	112.5
<b>60-64</b>	25.1	28.9	33.7	41.2	49.1	57.3	67.6
<b>65-69</b>	11.7	13.6	16.5	21.1	26.2	31.9	37.6
<b>70+</b>	2.9	3.3	4.0	5.2	6.5	8.0	10.0

Source: CDC Annual Series

I calculated the prevalence rate of AIDS and HIV among adults over the age of 25 by age category for specific time intervals using US Census Bureau Data and CDC Annual Series numbers. The prevalence rate for both AIDS (Table 2.2) and HIV (Table 2.3) remains relatively steady or decreases slightly for younger adults during the time interval stated. For older adults, it is increasing, and in some specific older adult categories, it is increasing dramatically. These rates include new



diagnoses and the fact that people are living longer with this disease and are aging in to the older adult categories.

**Table 2.2: Prevalence Rate per 100,000 of Adults Living with AIDS by Year and Age Category, 2000-2004**

Age Category	2000	2001	2002	2003	2004
25-29	72.7	70.4	68.8	68.9	70.2
30-34	196.6	184.9	175.9	169.2	164.5
35-39	319.1	328.6	332.3	330.9	324.9
40-44	317.9	338.7	363.4	390.4	415.9
45-49	266.2	292.8	316.7	342.1	369.1
50-54	177.8	199.0	230.0	257.0	288.9
55-59	109.6	126.9	140.3	161.4	182.2
60-64	66.6	76.5	89.2	95.2	113.0
65+	17.0	19.9	23.3	27.5	32.6

Source: CDC Annual Series and US Census Bureau Data

**Table 2.3: Prevalence Rate per 100,000 of Adults Living with HIV by Year and Age Category in 35 States, 2001-2004**

Age Category	2001	2002	2003	2004
25-29	133.6	136.1	138.9	142.5
30-34	253.9	249.1	243.4	240.1
35-39	370.3	380.5	382.6	380.5
40-44	347.2	365.5	406.4	432.7
45-49	284.9	309.6	333.1	360.4
50-54	187.1	216.5	241.2	276.5
55-59	116.8	129.6	148.1	175.3
60-64	60.1	82.6	91.6	108.7
65+	18.9	22.0	25.3	29.9

Source: CDC Annual Series and US Census Bureau Data

The actual numbers of older adults living with HIV and/or AIDS illustrates the same trend as that of the prevalence rates. In Table 2.4 below, the number of adults living with AIDS who fall into the 45-49 and 50+ age groups is tracked from the year 1994 to 2000. The numbers for both groups increase each year. Figure 2.5 below illustrates the same trend from years 2001 to 2004, with the only exception being that this is the number of persons living with either HIV or AIDS. These

numbers increase each year, with the 50+ population making up nearly 1 in 4 persons living with HIV or AIDS in 2004.

**Table 2.4: Number of 45-49 and 50+ Persons Living with AIDS, 1994-2000**

Age Category	1994	1995	1996	1997	1998	1999	2000
45-49 years	21,115	25,076	30,099	36,383	42,251	48,825	55,290
50+ years	19,420	22,517	27,303	34,219	42,123	50,560	60,926

Source: CDC Annual Series

**Table 2.5: Number of 45-49 and 50+ Persons Living with HIV/AIDS, 2001-2004**

Age Category	2001	2002	2003	2004
45-49 years	59,008	65,879	72,498	79,728
50+ years	65,655	77,351	89,415	104,260

Source: CDC Annual Series

Like the prevalence rates, I calculated the incidence rate of AIDS (Table 2.6) and HIV (Table 2.7) among adults over the age of 25 by age category for specific time intervals using US Census Bureau Data and CDC Annual Series numbers.

These are conservative estimates of the incidence rate of AIDS and HIV because I am using the entire population, and not just segments of the older adult population who are most at risk (gay men, intravenous drug users, single adults who are having sex, etc.). It is difficult to track the incidence and prevalence rates from earlier than 2000 because there has not been a standard data collection system for the epidemic. States were not even required to submit their HIV numbers until 2007 (as part of the Ryan

White CARE Act), so the following tables on HIV are based on the numbers from 33 and 35 states respectively.

**Table 2.6: Incidence Rate per 100,000 of New AIDS Diagnoses by Year and Age Category, 2000-2004**

Age Category	2000	2001	2002	2003	2004
25-29	17.8	17.1	17.3	17.1	18.3
30-34	31.6	30.2	28.9	28.9	28.3
35-39	39.4	38.8	39.9	40.9	38.2
40-44	33.4	32.8	34.1	36.1	37.9
45-49	25.9	26.1	26.6	28.0	28.2
50-54	16.9	17.1	18.4	19.3	20.2
55-59	11.3	11.3	11.4	11.8	12.6
60-64	7.7	7.4	8.1	7.7	7.9
65+	2.1	2.2	2.1	2.4	2.5

Source: CDC Annual Series and US Census Bureau Data

The incidence rate for AIDS and HIV was relatively steady or going down a bit in younger adults, which has been established in the literature. For older adults, the incidence rate is going up.

**Table 2.7: Incidence Rate per 100,000 of New HIV Diagnoses by Year and Age Category in 33 States, 2001-2004**

Age Category	2001	2002	2003	2004
25-29	24.3	23.8	22.5	23.6
30-34	32.7	30.3	27.5	27.0
35-39	37.1	35.3	33.2	32.1
40-44	29.3	27.9	28.2	27.5
45-49	22.7	21.2	20.7	20.5
50-54	14.7	14.1	14.4	14.2
55-59	10.4	8.8	9.0	9.7
60-64	6.7	6.6	5.8	6.4
65+	1.9	1.8	1.7	2.0

Source: CDC Annual Series and US Census Bureau Data

The numbers and percents of new diagnoses among older adults also show an increase since 1995. When looking at the new U.S. AIDS cases diagnosed between 1995 and 2004, the number of new U.S. cases newly diagnosed with AIDS during the

mid- to later older adult years has steadily increased (see Table 2.8 below for an illustration of this trend). The same trend occurred for new HIV diagnoses between 2001 and 2004 (see Table 2.9). These are new diagnoses and not an example of an older adult who had been diagnosed with HIV during their younger years and “aged” into older adult with HIV/AIDS.

**Table 2.8: Age at AIDS Diagnosis for 45-49 and 50+ Populations, 1995-2004**

Age	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
<b>45-49</b>	7,008	6,566	5,553	4,999	5,032	5,200	5,401	5,656	6,102	6,245
<b>50+</b>	7,249	6,647	5,896	5,554	5,594	6,120	6,345	6,822	7,303	7,908

Source: CDC Annual Series

**Table 2.9: Age at HIV Diagnosis for 45-49 and 50+ Populations, 2001-2004**

Age Category	2001	2002	2003	2004
<b>45-49</b>	4,709 (11.4% of US HIV population)	4,486 (11.4% of US HIV population)	4,514 (11.8% of US HIV population)	4,536 (11.7% of US HIV population)
<b>50+</b>	5,550 (13.5% of US HIV population)	5,363 (13.7% of US HIV population)	5,475 (14.3% of US HIV population)	5,908 (15.3% of US HIV population)

Source: CDC Annual Series

Older adults also make up a substantial percentage of the U.S. AIDS population who are dying of AIDS-related diseases (see Table 2.10 below). While many older adults might be aging into their mid-late years with AIDS or HIV, they are also dying of the disease at an increasing rate. Therefore, one cannot assume that the reason why the percentages of AIDS or HIV cases in this age group is rising steadily is due primarily to the fact that people are living longer with the disease

(though this is a trend). Because many older adults are diagnosed with AIDS without having been diagnosed with HIV, these percentages also likely include older adults who were diagnosed with AIDS shortly before their deaths.

**Table 2.10: Percent of AIDS Deaths for 45-49 and 50+ Populations out of Total US AIDS Deaths, 1995-2004**

Age	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
45-49	13.0%	13.9%	15.0%	16.4%	18.1%	18.0%	17.7%	19.2%	19.2%	19.1%
50+	14.3%	15.3%	17.6%	20.1%	22.5%	24.6%	26.6%	28.2%	30.6%	32.2%

Source: CDC Annual Series

Older adults who are 50+ years old made up nearly one in five of all of the newly diagnosed AIDS cases in 2004. The numbers of new AIDS cases among older adults has climbed steadily since 1998, and the percentage that this age group represents in the total U.S. AIDS population has nearly doubled in ten years (from 1995 to 2004). Furthermore, the 50+ population has increased in greater numbers and percentages than the 45-49 age group. Also very noteworthy is the fact that in 2004, one out of three AIDS deaths occurred in the 50+ population, a substantial increase from just ten years earlier (14.3% versus 32.2%). Some of these deaths should be expected considering issues of co-morbidity, especially since this age cohort has the highest percentage of those converting to AIDS within 12 months of HIV diagnosis. Additionally, the lack of HIV/AIDS testing or late testing in this age cohort could be contributing to earlier deaths.

In 2004 the CDC released the following trends in HIV/AIDS in the United

States, all of which occurred between 2001 and 2004:

- HIV/AIDS decreased in the following age populations: under 13, 13-14, 30-34, 35-39, 40-44, 45-49
- HIV/AIDS increased in the following age populations: 15-19, 20-24, 50-54, 55-59, 60-64, 65+
- AIDS cases increased in the following age populations: 40-44, 45-49, 50-54, 55-59, 60-64, 65+
- AIDS deaths increased in the following age populations: 50-54, 55-59, 60-64, 65+

The common response would be that the overall US population has increased, so the numbers and rates of HIV/AIDS should increase as well. But when looking at AIDS between the years 2000-2004, one can see that the incidence and prevalence percentages are increasing at a higher rate than the population is increasing among older adults (over the age of 50). In the younger adult categories under 50, these rates are decreasing faster than the population. This illustrates that HIV/AIDS is becoming a disease of middle and older age.

**Table 2.11: Comparison of Percents of Population Difference, AIDS Incidence Rates, and AIDS Prevalence Rates between 2000-2004**

Age Category	Population Difference	Incidence Difference	Prevalence Difference
<b>25-29</b>	1.2%	2.8%	-3.6%
<b>30-34</b>	-4%	-11.6%	-19.5%
<b>35-39</b>	-7.7%	-3.1%	1.8%
<b>40-44</b>	2.3%	13.5%	30.8%
<b>45-49</b>	9.4%	8.9%	38.7%
<b>50-54</b>	9.7%	19.5%	65.5%
<b>55-59</b>	21.6%	11.5%	66.2%
<b>60-64</b>	16.0%	2.6%	69.7%
<b>65+</b>	3.5%	19.0%	91.8%

Source: CDC Annual Series and US Census Bureau Data

For HIV, it is apparent that prevention education may be working...but it appears far more effective in the younger adult age categories than in the older adult age

categories, and new infections among the 65+ is actually increasing in comparison to the population.

**Table 2.12: Comparison of Percents of Population Difference, HIV Incidence Rates, and HIV Prevalence Rates between 2001-2004**

<b>Age Category</b>	<b>Population Difference</b>	<b>Incidence Difference</b>	<b>Prevalence Difference</b>
<b>25-29</b>	3.1%	-3.0%	6.7%
<b>30-34</b>	-1.4%	-21.1%	-5.7%
<b>35-39</b>	-5.9%	-15.6%	2.8%
<b>40-44</b>	.9%	-6.5%	24.6%
<b>45-49</b>	6.8%	-10.7%	26.5%
<b>50-54</b>	4.5%	-3.5%	47.5%
<b>55-59</b>	18.3%	-7.2%	50.1%
<b>60-64</b>	13.4%	-4.7%	80.9%
<b>65+</b>	2.8%	5.3%	58.2%

Source: CDC Annual Series and US Census Bureau Data

While the trends might be surprising to some, they were predicted in research from the late 1980s. Researchers found that the AIDS caseload data suggested that late-middle-aged and older adult people were at risk for sexually transmitting HIV (Catania et al. 1989a). It is evident from the information presented that this prediction is coming to fruition. The reasons for this increase in HIV/AIDS infections among older adults should be explored, but first I will examine the behaviors that older adults exhibit that may be putting them at risk.

### **Older Adults and Sexual Activity**

Due to a reduction in mortality Americans are living much longer and the older adult population is increasing (Cooney & Dunne 2001). During the time period between the last two U.S. censuses of 1990 and 2000 (US Census Bureau 1990; U.S. Census Bureau 2000) and the American Community Survey (2004), older adults over the age of 45 increased from 77.6 million to 104.3 million. Older adults over the age

of 50 increased from 63.7 million to 82.4 million during the same time period. The overall U.S. population stood at approximately 285.7 million citizens in 2004, meaning that older adults represent a large proportion of the U.S. population. What this means as far as the HIV/AIDS epidemic is that there are an increasing number of people in this age population who potentially could be at risk for contracting HIV by exhibiting specific behaviors such as having sex or sharing needles.

The risk behaviors that older adults exhibit are no different than those exhibited by younger adults. For starters, older adults, like members of other age cohorts, have sex outside of the confines of marriage. While the overall U.S. population's divorce rate has remained relatively stable or has even decreased in some age groups from 1990-2004, the 45-54 age group has the highest percentage of divorced adults and the 55-64 age group has the second highest percentage (National Center for Health Statistics 2005). The result is an increase in the number of older adults available to date in the future, and who are likely to have more sexual partners than previous cohorts of older adults. Additionally, studies show that men date more in midlife and continue to date longer than women, possibly due to the fact that society has fewer social prohibitions for men, and men have a larger field of eligible partners for dating than do women (Cooney & Dunne 2001; Thienhaus, Conter & Bosmann 1986).

Even if an older adult is married it does not mean they are not at risk for HIV infection, as older adults are not immune to having sexual affairs. While there is an assumption that older adults are monogamous, research suggests that this is not



necessarily true (Catania et al. 1989a). An AARP survey (2005) revealed that 7% of older adult respondents admitted to having sex outside of marriage without spousal consent, and 3% had sex outside of marriage with spousal consent. Keeping in mind that this 10% represents those who actually admit to having sex outside of marriage (and we can assume that the actual number is probably higher), there is the potential for an older adult to become infected and pass the virus on to their partner.

The risk for passing on the virus through sexual contact assumes that older adults are sexual beings. Contrary to popular cultural belief, it is not true that, because of age, older adults are destined to be sexually incapacitated (Riley 1988). In fact, research reveals that older adults have been shown to have sexual desires that persist well into advanced post-retirement age (Schlesinger 1996; Hodson 1994).

The AARP survey (2005) also uncovered information on the sexual activities of older adults. When asked if they had engaged in a sexual activity in the past 6 months, 99% of partnered older adults and 59% of single older adults answered “yes.” In a survey of adults over 60, 92.7% of men and 70.4% of women stated they were still sexually active (Inelmen, Meral, Gasparini & Enzi 2005). Echoing this finding, Lindau et al. (2007) recently found that the frequency of sexual activity reported by their older adult respondents was similar to that reported among the younger population (as young as 18) in the 1992 National Health and Social Life Survey. Additionally, the researchers found that a substantial number of older adults engage in vaginal intercourse and oral sex in their 80s and 90s.

Older adults who lived in long-term care facilities also participate in sexual

activities. The National Association on HIV over 50 (2005) reported that it is not unusual for prostitutes to visit assisted living and long-term care facilities.

Additionally, older adults in community care retirement centers may have increased access to a wider array of sexual partners. In their study, Orel, Spence and Steele (2005) find that this increase in sexual partners was as high as 65% after the older adults in their study entered a nursing facility or assisted living.

Even though there is evidence that they are participants in sexual activities, sex-seeking behavior of any type in older adults is often viewed as pathological (Simon 1986), and even frightens many people (Walz 2002). Older and elderly people are supposed to be less sexually eligible and sexless, and any contradiction to this is considered to be outside of the norm (Davidson & Fennell 2002; Libman 1989; Traupmann 1984). Even those who perform research on the topic of older adults and sexuality may hold on to lingering stereotypes. For example, Herron and Herron (1999) believe that sexual functioning is a positive and normal aspect of older married life, but they did not extend this to older single adults. Furthermore, some fields of research, particularly gerontology, have been criticized by researchers (Gott and Hinchliff [2003] for example) for not giving enough attention to the sexual issues associated with older adults and aging. As Lindau et al. (2007) found in their work, little is known about older adults' sexuality, despite the sheer volume of this population.

From the few who are doing research in the area, some insight has been gained. Gott and Hinchliff's (2003) work dispels the myth that sexuality and sexual

desire automatically decreases with age. Instead they found that the health problems older adults experience could be a barrier to remaining sexually active. For example, the effects of certain health problems on sexual function are often compounded by the side effects of many common medications prescribed for illnesses (Calasanti & King 2005; Kellett 1991; Rice 1989). The misconception of older adults as non-sexual beings may have a biomedical component to it, and might not necessarily be a component of the aging process itself.

### **Public Health, Older Adults and HIV/AIDS**

White and Catania (1982) argued over 25 years ago for the need for sex education interventions for older adults, yet in many ways, this need fell on deaf ears. Older adults are almost universally excluded from educational campaigns concerning sex education (Strombeck and Levy 1998). Furthermore, Poindexter and Keigher (2004) claim that older adults are often forgotten in designs of risk reduction and prevention programs at the state level, including those for HIV/AIDS. This is a dangerous trend, because a significant proportion of older adults follow a high-risk trajectory towards HIV infection, sometimes even more so than younger adults. For example, older adults are far less likely to be tested for HIV than younger cohorts and are often diagnosed at a later disease stage than younger adults. According to Genke (2000), a national survey revealed that older adults were one-fifth as likely to be tested for HIV infection as younger adults. Another study revealed that 95% of participants over the age of 50 who provided survey responses had never been tested for HIV (Inelmen, Gasparini & Enzi 2005). Because testing may help to reduce

transmission rates and curb dangerous behaviors related to HIV infection, infected older adults who do not know their status may be unknowingly infecting others (Wolf, Donoghoe & Lane 2007).

Overall, older adults by far are the age group that lacks the most knowledge about HIV/AIDS or their perceived risk for infection (Coon, Lipman & Ory 2003; Gallagher & Petersen 1992). In addition, older adults tend to not protect themselves against HIV infection through the use of condoms. According to the 1996 National Household Survey of Drug Abuse (Substance Abuse and Mental Health Services Administration 1997), the older adult cohort was the least likely by far of all age cohorts surveyed to use condoms in their previous sexual encounter, even when the encounter was casual and not part of a relationship. Genke (2000) and Inelmen et al. (2005) found similar results in their research, with one study revealing that 92% of older adults over the age of 50 never used condoms. Perhaps this is due to the fact that some older adults associate condoms as being a form of birth control; once women are past the age of menopause, there is no longer a risk of pregnancy. This combined with a low level of knowledge about HIV/AIDS—nearly half of the older adults in one study knew little or nothing about AIDS (Mack & Bland 1999) — could be the reason why condom use is so low among older adults.

Several researchers voice a concern about this low level of HIV/AIDS knowledge among older adults, especially older women. Emler, Tangenberg and Siverson (2002) found that older women have a lesser perception of risk of contracting HIV and less knowledge of safe sex practices than younger women. This

is especially dangerous as older women are one of the fastest growing groups of newly infected individuals. In fact, Mack and Bland (1999) contend that older women are more at risk for HIV than older men because they are more likely to be unmarried, to be involved in a variety of sexual encounters, to never have used condoms, and to have a more rapid progression to AIDS.

The perception of not being at risk for HIV/AIDS is common among older adults. According to research (Coon, Lipman & Ory 2003; Ory & Mack 1998), older adults have made fewer behavioral accommodations to avoid risk for HIV/AIDS infection because their risk perception is low. Additionally, it is taken for granted that older adults somehow cannot transmit the virus because they are not believed to be interested in sex (Riley & Riley Jr. 1989). However, the number of new HIV infections and AIDS diagnoses among older adults tell us that they are at risk, either through sex or drug use (Inelmen, Meral, Gasparini & Enzi 2005; Heckman, Kochman, Sikkema & Kalichman 1999). Among the newly infected older adult population, heterosexual sex was the primary mode of transmission (THJKFF 2007g; ACRIA 2006; Emlet, Tangenberg & Siverson 2002; Stombeck & Levy 1998). In fact, the largest percent of AIDS cases among any heterosexual group is in the older adult age group (Williams & Donnelly 2002).

Table 2.13 below shows the mode of AIDS transmission by new diagnoses in the older adult population during two different years. The most commonly perceived mode of transmission, homosexual sexual contact, stayed relatively steady during the two time intervals. Heterosexual contact as a mode of

transmission doubled, and injection drug use as a mode of transmission increased as well. Granted, the “other” category as a mode of transmission decreased dramatically. This may be due to older adults being reluctant to admit to using injection drugs or being at risk because of heterosexual sex. But the fact that nearly a third of new diagnoses were due to heterosexual sex should be alarming for older adults who never viewed themselves as being at risk.

**Table 2.13: Mode of AIDS Transmission by New Diagnoses in 50+ Population, 1996 and 2000**

<b>Mode of Transmission</b>	<b>1996 New Diagnoses</b>	<b>2000 New Diagnoses</b>
<b>Male-male sexual contact</b>	2,674 (35.9% of New Diagnoses)	2,140 (35.6% of New Diagnoses)
<b>Injection drug use</b>	1,430 (19.2% of New Diagnoses)	1,789 (29.8% of New Diagnoses)
<b>Male-male sexual contact and Injection drug use</b>	166 (2.2% of New Diagnoses)	214 (3.6% of New Diagnoses)
<b>Heterosexual contact</b>	1,084 (14.5% of New Diagnoses)	1,717 (29% of New Diagnoses)
<b>Other</b>	2,105 (38.2% of New Diagnoses)	151 (3% of New Diagnoses)
<b>Total</b>	7,459	6,011

Source: CDC Annual Series

In addition, it might be surprising to think of older adults as being injection drug users, but nearly 30% of new diagnoses stem from infections due to injection drug use. No one wants to think of their parent or grandparent as using drugs, but growing older does not necessarily correlate with giving up dangerous behaviors stemming from younger adulthood. While the stigma of an older adult contracting the virus through sex certainly exists, the stigma of being an IV drug user in older adulthood carries an even bigger stigma.

There are a few possible reasons why older adults do not correctly perceive their risk level. First, from the beginning of the HIV/AIDS epidemic, the media has

powerfully influenced whom the public thought was at risk for infection (Holland, Ramazanoglu & Scott 1990). According to Short Jr. (1984) and Stallings (1990), media coverage heavily influences public awareness of risks. In fact, Stallings (1990: 80) claims that “news organizations are one of the most significant actors involved in the social construction of risk.” Media coverage of the early years of the epidemic had a powerful impact on how the U.S. understood AIDS. During the first two years of the epidemic, the mass media virtually ignored the outbreak of the new disease. When the first news report was published in the mainstream media (two years after the disease first appeared in five gay men), its title—“The Gay Plague”—not only set into motion the stigmatization of a sub-group of the population, but also set a precedent that AIDS was a strictly gay disease. This left most of the US feeling as though they were far removed from being at risk. Because older adults rarely are the focus of media depictions of people with HIV/AIDS, they may not identify themselves as being at risk.

Second, those who are part of older adult age cohorts (both pre-retirement and post-retirement ages) may have come of age during a time of strict moral sanctions, resulting in the reluctance to discuss any sexual issues in public or with their physician (Genke 2000; Catania et al. 1989b). Discussion about sex and condoms may be an embarrassing subject for older adults, especially if they are talking to a younger physician. Further, older adults who use intravenous drugs or visit prostitutes might not be willing to admit this, and are therefore probably not going to get tested for HIV. Older adults, especially those in their later years, may be

unwilling to discuss any behaviors seen as risky because of the stigma attached to these behaviors (ACRIA 2004). Flavo and Norman (2004) found that this unwillingness to discuss risk behaviors also contributed to the difficulties that exist in finding representative samples and individuals willing to participate in HIV/AIDS research among older adults.

Third, ageist attitudes and assumptions continue to dominate our culture. Not only does our society ignore the fact that older adults are sexual, but there is an assumption that older adults know how to avoid HIV infection simply by virtue of being older. Based on the increase in new infections among older adults, prevention education might not be reaching everyone in this particular age group. With the advent of sexual enhancing drugs for erectile dysfunction and hormone replacement therapy, the importance of HIV/AIDS prevention education is even greater.

### **The Pharmaceutical Impact: Causing a Rise in HIV/AIDS among Older Adults?**

In the past, the decline of sexual desire was thought to be a symptom of an aging body (Calasanti & King 2005). However, the March 27, 1998 release of Viagra changed what was thought to be inevitable, as the contemporary construction of functional sexuality got a boost from a biomedical intervention (Katz & Marshall 2004). Viagra and its imitators (Cialis and Levitra, for example) are medications used to treat erectile dysfunction in men. Those who previously “lost” their sexual energy due to illness or medications they were taking were able to regain this vitality. The introduction of Viagra was seen as having a substantial and important effect on the sex lives of older adults. Older adult men certainly understood this fact, as over



17 million prescriptions for Viagra were written for older men from 1998 to 2000 alone (Emlet & Farkas 2001). Currently, one in seven older adult men reported taking medication to improve their sexual functioning (Lindau et al. 2007).

While the Viagra revolution and the pharmacology of sex arguably has had a positive effect on the sexual lives of middle-aged and older adults, it could also be contributing to the growing rate of HIV infection and AIDS diagnoses among older adults. Vance and Robinson (2004) argue that the evolution of Viagra and its acceptance in mainstream society has increased the potential for HIV transmission among previously partnered older adults who are either seeking new partners later in life or for the first time in many years. Researchers believe that the baby boomer generation who lived through the sexual revolution of the 1960s has more risky sexual and drug-related behaviors than most other age groups (Ory & Mack 1998). This, in conjunction with the introduction of erectile dysfunction medications, may increase the HIV/AIDS rate at an alarming rate (Levy-Dweck 2005).

Emlet and Farkas (2001: 226) argue that the HIV infection rate among older adults—and especially men—is spreading like a “forest fire.” In recent studies of gay and bisexual men, an increased vulnerability to HIV infection was found among those who use erectile dysfunction drugs (Sanchez & Gallagher 2006; Chu et al. 2003; Kim et al. 2002). A study by the San Francisco Department of Public Health (2005) revealed that newly HIV infected individuals were two and a half times more likely to be users of erectile dysfunction drugs. This finding resulted in a direct request by public health officials to drug manufacturers to address the risk of HIV infection and

its association with the erectile dysfunction drugs. In 2007, an AIDS foundation in California sued Pfizer (the maker of Viagra) for using deceptive marketing of Viagra (i.e., telling consumers they can be sexually young again), which they saw as contributing to the spread of HIV/AIDS and other STDs (AIDS Healthcare Foundation 2007; THJKFF 2007a; THJKFF 2007b).

While no direct correlation can be made, there are indications that the pharmacology of sex has had some effect on the HIV and AIDS rates among the older adult population. Table 2.14 below illustrates that the numbers of AIDS diagnoses in the 50+ age group fell steadily between 1994 and 1998, and the numbers of AIDS diagnoses in the 45-49 age group fell steadily between 1995 and 1998. Viagra was first introduced to the public in early 1998. The number of AIDS diagnoses began to rise steadily in 1999 and continued to increase in both age cohorts through 2004. These are new diagnoses, and therefore “aging in with AIDS” is not a factor.

**Table 2.14: Age at AIDS Diagnosis, 45-49 years and 50+ years, 1994-2004**

Age	94	95	96	97	98	99	00	01	02	03	04
45-49	6,989	7,008	6,566	5,553	4,999	5,032	5,200	5,401	5,656	6,102	6,245
50+	7,396	7,249	6,647	5,896	5,554	5,594	6,120	6,345	6,822	7,303	7,908

Source: CDC Annual Series

A recent Los Angeles Times article points out that, as people stay sexually active longer because of these erectile dysfunction drugs and hormone replacement therapy, there is a growing concern that older adults do not understand that getting older does not make them immune to infection (Huffstutter 2007; THJKFF 2007h). Perhaps an even more important point is that the physicians who prescribe these medications to their older adult patients are not necessarily talking to them about

using protection in conjunction with the drugs (if they are not in a monogamous relationship). This is especially dangerous considering that Klausner (2002) found that Viagra users have 35% more sexual partners and 35% more STDs than non-users.

Older women are arguably seeing the effects, and bearing the brunt, of the Viagra revolution. Levy-Dweck (2005) stated that nearly two-thirds of newly infected women over the age of 50 contracted HIV through heterosexual sex. In fact, heterosexual contact as the primary exposure route is higher for older women than younger women (Mack & Ory 2003). Further, Mason's (2003) research revealed that the increase in the number of older women diagnosed with STDs was due to unprotected sexual contact with men who took Viagra. As online pharmacies continue to fill prescriptions for Viagra without any direct physician-patient contact (and therefore no possible education on using protection), this number may continue to increase (Ferri 2005).

### **Physician Denial about Older Adults' Risk**

Contracting HIV or AIDS is not what people necessarily think of as an older adult issue, and the denial about their potential to become infected is prevalent among many care providers (Langley 2006; Hayes Taylor 2004; Coon, Lipman & Ory 2003; Orsulic-Jeras, Sepher & Britton 2003). Physicians and health practitioners are also ignoring the sexual needs and, more importantly, the sexual education of older adults. In their research on whether or not physicians discuss issues related to sexuality with their older adult patients, Gott, Hinchliff and Galena (2004) found that physicians

were more likely than not to hold stereotypes about older adults and sex. For example, the physicians they interviewed equated sexual health with younger people, and did not give any type of prevention advice to older adults. According to a study by the National Institutes of Health, only 38% of men and 22% of women over the age of 50 discussed sex with their physician (Huffstutter 2007). Overall, sexual histories are not routinely included in patient assessments of older adults (Inelmen, Gasparini & Enzi 2005).

Other studies confirm these findings. Researchers found that primary care physicians are less likely to discuss HIV risk reduction with their patients over the age of 50 than with patients under the age of 50 (Williams & Donnelly 2002). Further, Falvo and Norman (2004) found that only 10.8% of persons over the age of 50 discussed HIV/AIDS with their physicians. Similarly, a study done by the CDC revealed that, even though physicians are in an excellent position to provide HIV/AIDS prevention education to older adults, only 31% of doctors discuss condom use, 27% discuss sexual orientation, and 22% discuss the number of sexual partners an older adult has (Stombeck & Levy 1998). As Gott, Hinchliff and Galena (2004) explained:

Safe sex was not seen as a relevant topic to discuss with middle aged and older patients, reflecting very clearly both policy priorities and wider societal beliefs that it is *only* young people who engage in risky sexual practices (2101).

Instead of viewing sexuality in the aged as a positive aspect of aging, some research suggests that medical professionals view it as something to be eliminated (Schlesinger 1996). This might not necessarily be the fault of physicians alone.

Lindau et al. (2007) point out that no comprehensive or nationally representative population-based data are available to inform physicians about the sexual norms and problems of older adults. Further, older adult patients are reluctant to initiate discussions about sex, perhaps due to the age differences between the patient and the physician (Huffstutter 2007; Kilgannon 2007; Nusbaum, Singh & Pyles 2004; Brooks Jr 2003; Siegel, Raveis & Karus 1998). Even the CDC is ignoring large segments of the older adult population (specifically anyone over the age of 65) when they recommended routine HIV testing for all Americans between the ages of 13 and 64 (Wolf, Donoghoe & Lane 2007). Therefore, it is not necessarily a surprise that many physicians are not offering an HIV test to their older adult patients.

Among those who do become infected, there are challenges that older adults face that younger adults might not necessarily encounter. These include misdiagnosis, co-morbidities, and mental health issues. HIV-related illnesses can be very difficult to distinguish from other so-called “typical” age-related health issues. For example, research shows that age-related diseases such as Alzheimer’s, arthritis, breast or prostate cancer, diabetes, vision/hearing loss, and high blood pressure all share common symptoms with HIV/AIDS (ACRIA 2004; Genke 2000; Avis & Smith 1998). This has become so common that Mack and Bland (1999: 687) labeled the disease in older adults as the “new great imitator” due to its resemblance to other conditions related to aging.

AIDS-related illnesses also tend to be more severe in older adults, because opportunistic infections are likely to develop differently in older adults. Additionally,

late diagnosis affects the overall survival rate, with older adults being more likely to be diagnosed with AIDS without ever having been diagnosed with HIV, mostly due to not being tested (Emlet, Tangenberg & Siverson 2002; Emlet & Farkas 2001; Justice & Weissman 1998). Siegel, Dean and Schrimshaw's (1999) found that most of the older adult participants of their study were HIV-positive and did not even know it, because they believed their symptoms were associated with normal aging.

HIV/AIDS also has gender implications, as older adult women are overwhelmingly excluded from any type of HIV/AIDS research and intervention. This exclusion is so common that Emlet and Farkas (2001) refer to them as "invisible victims" who are ignored by health care providers, researchers, and policymakers. This is especially dangerous for older women, who were among the fastest growing populations infected with HIV recent years. Keigher, Stevens and Plach (2004) find that the number of AIDS cases among middle aged to older women more than tripled between the years 1985-1999. In fact, when looking at the numbers of new infections and diagnoses among women, the incidence of new cases actually increased with age (Brooks Jr. 2003; Genke 2000; Zablotsky 1998).

So what information on older adults and HIV/AIDS is missing? We know that there exists a misconception that older adults do not need HIV/AIDS education because they do not participate in practices that put them at risk. We also know that many physicians do not necessarily discuss sexual issues or protection methods with older adults. And we know that older adults themselves are continuing to practice behaviors that may be putting themselves at risk for infection. But there are things

we do not know based on the existing research on older adults and HIV/AIDS. We do not know the extent to which older adults are included in HIV/AIDS prevention education and outreach. If they are excluded, we do not know the reasons for the exclusion.

### **Theoretical Resources**

#### *Sexual Scripts*

While humans may believe that what we do sexually, and in the context in which we do it, have some sort of biological basis, we also must acknowledge that the basic biological instinct of the sexual drive are controlled by cultural and societal norms. It is easy to use biology as the underlying explanation for sexual behavior because, as Gagnon and Simon (1973) believe, most people are blind to the fact that we follow scripts that define situations, labels and names of the actors, and the plots of behavior. Sexual scripts—which are firmly nested in a social constructionist and symbolic interactionist approach (Lewis and Kertzner 2003; Weinberg et al. 1983)—guide sexual behavior. They involve an organization of the sequences of specifically sexual acts, the decoding of novel situations, the setting of limits on sexual responses, and linking the meanings of nonsexual life aspects to sexual experiences.

There are 3 levels of sexual scripts: (1) cultural scenarios, which are general guides to sexual behavior such as who is an appropriate object of sexual desire, the appropriate relationship between sexual actors, appropriate time and places for sexual activity, etc.; (2) interpersonal scripts, which are individuals' interpretations of cultural scenarios, or an understanding of the cultural scenarios combined with

personal socialization and experiences; and (3) intrapsychic scripts, in which there is an internalization of socially shared scripts and scenarios (Parsons 2004; Whittier 2001; Hynie et al. 1998; Simon 1986; Simon & Gagnon 1984). In other words, all sexual behavior is embedded with cultural norms and patterns based on interactions with social structures (Shoveller et al. 2004; Parsons 2004; Bardella 2002). Different sexual scripts exist based on a person's race, ethnicity, gender, sexual preference, religion, age, etc.

Researchers point out that our beliefs about what are considered to be “normal” and “appropriate” sexual behaviors are firmly entrenched in society or specific communities (Shoveller et al. 2004; Gott & Hinchliff 2003; Simon 1999; Gavey, McPhillips & Braun 1999). “Normal” sex is the standard by which we define our differences and measure our inadequacies (Gavey, McPhillips & Braun 1999). In many ways, sexual scripts serve as a type of social regulation of sexual behavior due to set standards and constructed norms. Both social and cultural expectations of sexuality permit only certain forms of physical expression between appropriate partners in approved relationships (Davidson & Fennell 2002). Social sanctions reinforce these cultural ideas about relationships and appropriate sexual behavior through the threat of ridicule, possible ostracism, and especially stigma.

Each culture gives shape to unique sexual scripts through symbolic and learned aspects rather than biological drives (Bardella 2002; Netting & Burnett 2004). Simon and Gagnon (1984) point out cultural scenarios are instructional guides that influence an individual to become an active participant in shaping their own



behaviors based on appropriate cultural scripts. Additionally, Simon (1986) believes that the association of age in sexual domains exists, as do certain expectations as well as limitations. In the case of older adults, societal norms stipulate that they should be androgynous; sexuality is rarely anticipated in cultural scripts dealing with older adults. However, as researchers have found, many older adults do not adhere to prevailing cultural sexual scripts that say they should be asexual as they grow older. There is some indication that our culture has not advanced very far in our acceptance of older adults as sexual, even as older adults ignore the cultural sexual scripts and continue to have sex.

The cultural and sexual scripts of older adults can be difficult to understand. On the one hand, society is telling older adults that they are not sexual beings, and therefore are not at risk for contracting HIV/AIDS. But on the other hand, physicians are prescribing Viagra, Cialis, and Levitra (erectile dysfunction drugs) and hormone replacement therapy in increasing numbers to older adults, and the television commercials for this classification of drugs are touting the positive side of regaining a once-lost sexual vitality. Researchers (Berkeley & Ross 2003) point out that receiving mixed messages from the surrounding social world is considered one of the main reasons for adhering to risk-taking sexual behavior. If physicians, public health officials, and the media are not relaying the message that older adults are at risk for contracting HIV/AIDS, why would they stop exhibiting behaviors that put them at risk?

While much research has been done on sexual scripting theory, little research

exists on the sexual scripts of and about older adults (or the perceived sexual scripts of older adults). More importantly, there is a gap in research on how the perceived sexual scripts of older adults may increase their risk for HIV/AIDS. Sexual script theory may explain what the social norms are concerning older adults and sexuality, and how these social norms inform or influence the opinions of authorities who participate in providing HIV/AIDS prevention education services. Specifically, sexual script theory may help to answer the questions: Are older adults left out of HIV/AIDS prevention education policies? If older adults are left out of HIV/AIDS prevention education policies, what are the possible reasons? Do the reasons for the omission of older adults from HIV/AIDS prevention education policy have to do with the perceived sexual scripts and stereotypes state policymakers and ASO personnel believe about older adults? Do state policymakers and ASO personnel believe that older adults are not at risk for HIV/AIDS infection because it is not the social norm for older adults to partake in high-risk behaviors?

### *Risk*

When analyzing an epidemic such as HIV/AIDS, dialogue about risk must always be at the forefront of any discussion. Using a sociology of risk framework, risk is seen as the “potential for realization of unwanted, negative consequences of an event” (Tierney 1999: 106). Risk and risk estimates are viewed as social constructions derived from social and cultural factors. While risk has been a sociological issue for a few decades (with the most well-known approach of risk being the perspective of the “risk society” by Ulrich Beck [1992]), Zinn (2006)

argues that there is comparatively little theoretical integration of risk into research. Sociologists conceptualize risk as having elements of uncertainty that help to shape perceptions and behaviors (Prohaska et al.1990).

I argue that a risk framework is appropriate for this research on HIV/AIDS because of how risk has been based on socially constructed beliefs throughout the existence of the epidemic. For instance, risk is seen as the “likelihood or probability of some adverse effect of a hazard” and is scientifically measured and managed by both public and private domains (Short Jr. 1984). The United States public health approach to this epidemic has been to measure the probability of being infected by the virus based on group associations versus actual behaviors. When considering Heimer’s (1988) argument that the estimation of risk is based on a series of heuristics (or mental images that replace knowledge) and biases, it is easy to see how risk applies to the HIV/AIDS epidemic.

Another argument for using risk as a framework for this research is the idea that risk is socially constructed through different social organizations that create, filter, and distribute risk (Stallings 1990). A prime example of this is the media, who played an integral part in the framing and disseminating of information concerning the epidemic. Prohaska et al. (1990) find that, in order to estimate personal risk, individuals need some standard against which to assess their own risk. Based on how the media reported the epidemic (i.e., the “Gay Plague”) and the images being broadcast to the general public, many people were left with the false impression that, they were not at risk because they did not hear or see differently. This creation,

filtering, and disseminating of risk information during the formative years of the HIV/AIDS epidemic has resulted in lingering stereotypes and a false sense of security that most of the public is not at risk despite practicing risky behaviors.

According to the World Health Organization (2002), the perceptions of and reactions to risk are often shaped by past experiences, as well as information received from social actors—family, society and government. Risk is the most salient feature of leading models of health behavior used to combat disease (Prohaska et al.1990). Arguably the most utilized model of health behavior has been the health belief model, used since the 1950s by public health officials to predict health behaviors and perceptions of risk. This model posits that preventive health behaviors result from the perceived susceptibility to the health risk, perceived severity of the health risk, the benefits of preventive behavior versus the costs of preventive behavior, and self-efficacy (Ostermann et al. 2007; Strecher & Rosenstock 1997; Prohaska et al. 1990). The health belief model has been used in various public health arenas, and parts of the model continue to be used in current health promoting ventures.

For instance, similar to the health belief model, the current trend (or, as Schiltz and Sandfort [2000] call it, the prevailing sexual script) of promoting health and diminishing risk that public health officials use for the HIV/AIDS epidemic is recognizing that each individual has full responsibility over their own health via behavior modifications and risk management (Nettleton & Bunton 1995). Public health officials use strategies designed to meet the needs of specific groups within a population or the entire population itself through assessments, evidence-based

practices, and investments in health projects and community planning (Wallace 2005; Lefebvre 2002; Macdonald & Bunton 2002; Office of Disease Prevention and Health 2000a, Office of Disease Prevention and Health 2000b; Quah 1998; Osujih 1997; Burrows, Nettleton & Bunton 1995; Fox 1988). For example, individuals are given the tools at the community level—often through education and targeted outreach—to assess their own risk level for contracting HIV/AIDS. ASOs and state policymakers provide prevention education and it is up to individuals to decide whether or not to change their behaviors based on their risk perception.

While prevention education is a key component in assessing individual risk levels, there is the danger that those who do not adhere to preventive health behaviors and contract a specific disease will be stigmatized and considered deviant in some way. This is an underlying problem of the preventive health approach and in risk assessment. If a disease is deemed as preventable by adopting certain behaviors, then those who do become sick are seen as being at least partially to blame for their illness (Nelson, Schwartzberg & Vergara 2005; Pringle, Wells & Merrill 2004; Weare 2002; Davison & Smith 1995; McLeroy & Crump 1994). For example, 40% of deaths are said to be caused by behavior patterns that could be modified by preventive interventions. As McGinnis, Williams-Russo and Knickman (2002: 82) found, “behavior patterns represent the single most prominent domain of influence over health prospects in the United States.”

Another characteristic of a risk framework is that citizens first accept the way risks are framed by the government and then later modify their thinking and reframe

their choices (Healy 1999; Heimer 1988). There are certain elements that Nathanson (1996) believes are essential to the construction of credible risks. First, there must be an authority (the government, for example) who can define the danger that threatens. Next, there must be a causal chain to account for the danger. And finally, there is the designation of potential victims, and whether or not they are innocent or culpable. This pattern was certainly evident during the early years of the HIV/AIDS epidemic. The government decided that certain groups were at risk for infection, and who deserved to become infected due to practicing certain types of behaviors versus those who were considered to be innocent victims. The enduring stigma associated with this early construction of HIV/AIDS risk has yet to be shaken, as Fernandes et al. (2007) found in their work on AIDS stigma versus the stigma associated with other diseases. HIV/AIDS continues to have the highest level of stigma than any other disease, and having AIDS still is perceived as a punishment for personal irresponsibility or immoral behavior.

Since the beginning of the epidemic, AIDS preventive policy has been driven by the idea that it is an individual's responsibility to protect him or herself from behaviors that may unnecessarily expose them to the virus. At the same time, educating the public about their risk for HIV/AIDS infection is not considered a priority. Wilkinson (2001) argues that, while most people are aware of the social problems related to health risk, they do not necessarily perceive themselves as being "at risk" from hazards. This is especially true among older adults who continue to participate in risky behaviors because they do not perceive themselves as being at

risk for HIV or AIDS (Falvo & Norman 2004). Research reveals that an obstacle to educating older adults about HIV/AIDS is the lack of perceived relevance to their lives (Altschuler, Katz & Tynan 2004). This is not surprising, considering how the government and media outlets have framed the epidemic and risk categories.

### **Moving Beyond Theory**

While older adults are increasingly becoming a prominent part of the HIV/AIDS population, the sexual scripts that society holds for older adults and the low perception of risk among this population are perhaps keeping older adults from receiving the prevention education that they need. The lack of interest in older adults' risk for HIV/AIDS infection appears to be based on ageist assumptions and misconceptions. Altschuler, Katz and Tynan (2004) argue that it is society's views and misconceptions about older adults that may be putting them at risk. They state (122):

Old people are no longer interested in sex; if they are interested, no one's interested in them; if they do have sex, it's within a monogamous, heterosexual relationship; they don't do drugs; and if they ever did, it's so long ago it doesn't matter.

Mack and Bland (1999) argue that an overall interest and commitment to reducing HIV/AIDS in older adults has been a lower national priority than for younger persons. Perhaps this is due to older adults having less life to live than younger adults by virtue of life expectancy, or because our culture is blind to the potential risks that face older adults. According to Catania et al. (1989b), it was becoming increasingly apparent in the 1980s that greater attention needed to be paid to the transmission risks and prevention needs of older adults, but the warning was

not heeded. In a continuation of their research, Catania et al. (1989a) suggested a plan to address the impending HIV/AIDS crisis among older adults in 1989. This plan called for HIV/AIDS media campaigns that would focus on older adults, encouraging them to talk to professionals about how to protect themselves from infection.

On the surface, these suggestions do not seem to have been taken seriously, as the numbers of infected older adults is increasing. A lack of HIV/AIDS prevention education for older adults could be a cause for the increase, which is unfortunate considering research shows that older adults are much more likely than younger adults to engage in health promoting behaviors when they understand the benefits (Falvo & Norman 2004). As these trends continue to show that older adults are at risk for infection, the need for research into the theories and assumptions held by service providers that might impeded HIV prevention efforts among older adults is increasing (Coon, Lipman & Ory 2003).

Addressing these needs is important because of the social and financial implications that the increasing number of HIV/AIDS cases among older adults will continue to have. Older adults utilize more health care dollars than any other age group, and there are predictions that this will cause an even bigger strain on the nation's health care industry (Orel, Spence & Steele 2005). According to research (ACRIA 2006), the aging HIV/AIDS population faces a system of health care and social supports that is not prepared to meet its needs. Further, older adults may find fewer HIV/AIDS community support systems available to them than those available



to younger adults, which may explain why older adults as a whole are not accessing ASOs or getting tested for HIV/AIDS (Neundorfer, Camp, Lee, Skrajner, Malone & Carr 2004; Avis & Smith 1998).

ASOs are central to this research because they are on the front line of prevention education to the community. However, ASOs are not necessarily meeting the needs of all members of the community. As Healy (1999: 538) explained, “In the face of an obvious disaster we find that organizations tend to be slower to react and are less flexible than they should be.” For older adults, it appears that stereotypes and a lack of information continue to limit them from receiving educational and medical attention/direction in avoiding possible infection (Levy-Dweck 2005). In fact, ACRIA (2004) found that, in their research on older adults and HIV/AIDS risk, older adults are often ignored by medical personnel and ASOs. They state:

Until healthcare providers and AIDS service organizations recognize that older adults are at risk and need appropriate prevention interventions and treatment education programs, older adults will have to squeeze into existing programs to receive the services they need. (15)

There has been limited research on ASOs themselves, as well as prevention education and how it pertains to older adults. In order to ascertain whether the research conducted by ACRIA and other researchers is representative of ASOs and policies in the Midwest, I used qualitative methods and analyzed data from different sources. The next chapter explains the methodology and procedures used to perform the research on ASOs and state policymakers.

### **Chapter 3: Methodology and Procedures**

Sociologically speaking, there is a virtual cornucopia of research in the area of HIV/AIDS. In fact, Bosk and Frader (1997) refer to HIV/AIDS as a “total social phenomenon,” involving economic, political, cultural, and social dimensions in addition to the core medical experience (225). However, older adults have been conspicuously absent from much of this research (Falvo & Norman 2004; Stombeck & Levy 1998). My dissertation addresses the increasing HIV/AIDS crisis among older adults, and specifically whether or not HIV/AIDS prevention and education campaigns are being aimed towards older adults, in order to address this gap in the research, as well as to gain insight into the underpinnings of public health policy.

In order to accomplish this task, I implemented a multi-method strategy that included: 1) semi-structured qualitative interviews with state HIV/AIDS policymakers and ASO Executive Directors and other personnel; 2) an organizational ethnography of an ASO; 3) attendance at state HIV/AIDS consortia meetings; and 4) a content analysis of state HIV/AIDS plans. I investigated HIV/AIDS prevention and education policies both at the state level and at the community level to decipher if older adults were left out of prevention education and if so, the reasons for the omission. Several questions guided my research: Are older adults indeed overlooked by HIV/AIDS prevention education campaigns? If they are omitted, is it because policymakers and health professionals do not think older adults exhibit enough risk behaviors for HIV? Is it a lack of public health funds? How do sexual scripts shape behaviors in older adults and HIV/AIDS education and outreach by public health

policymakers? How do social factors influence HIV/AIDS education/prevention services targeted towards older adults?

I believe that the methods I chose to investigate the HIV/AIDS epidemic in the Midwest are appropriate for answering the questions that guided my research. Through the semi-structured qualitative interviews with state HIV/AIDS policymakers and ASO Executive Directors and other personnel, I was able to decipher if older adults were overlooked by HIV/AIDS prevention education campaigns, if policymakers and health professionals did not think older adults exhibit enough risk behaviors for HIV, if a lack of public health funds was the reason for the omission, and the extent to which sexual scripts had an impact on HIV/AIDS education and outreach by public health policymakers. My interview questions were influenced by these research questions. Through the conduction of an organizational ethnography of an ASO, attendance at state HIV/AIDS consortia meetings, and a content analysis of state HIV/AIDS plans, I was able to answer the question: How do social factors influence HIV/AIDS education/prevention services targeted towards older adults?

In order to fully understand the situation with HIV/AIDS prevention education and health promotion occurring in the Midwest, the data I collected were based on multiple phases of fieldwork. I attempted to exhaust every potential source of primary data through interviews, an organizational ethnography, and other sources of primary data in order to exhibit coherence and continuity in my work. The following is an explanation of my research methods and procedures that I implemented for this

dissertation.

## **Research Methods**

### *Qualitative Interviews*

The crux of my research is based on the interviews I conducted with Executive Directors, Prevention Directors, and/or Case Managers of ASOs, and state HIV/AIDS policymakers (State AIDS Directors, Prevention Directors, Surveillance Coordinators, Ryan White Titles Directors, etc.) in four states in the Midwest. I chose to perform my research in the Midwest for three reasons. First, the Midwest is certainly not a focus in much HIV/AIDS research, and I found very little mention of HIV/AIDS research being conducted in the Midwest. Traditionally, research on HIV/AIDS has typically been conducted on the East and West coasts, where the epi-centers of the U.S. HIV/AIDS crisis have been located. More recently HIV/AIDS research has increasingly focused on the South, which has seen an increase in both the number and the rate of new HIV/AIDS cases. The Midwest, however, continues to be understudied. My dissertation will attempt to fill this research gap and provide new insight into the HIV/AIDS crisis in this region.

Second, the Midwest is a unique region to study for a few reasons. Despite not being thought of as a hotbed of HIV/AIDS activity, the Midwest was the region with the largest percent of new AIDS diagnoses between 2001 and 2005. Along with this increase in the number of individuals with HIV/AIDS, there is the issue of restricted care available for those who are infected. Researchers (Preston et al. 2002; Roeder 2002) call for attention to these areas, as the HIV/AIDS community

is not being effectively treated for the disease. In addition, rural service providers, rely heavily on ASOs for prevention, education, and case management assistance more than they do in urban areas. Due to this reliance, ASOs in the Midwest were an important part of my research.

Third, I chose to focus on the Midwest simply due to the fact that I have strong ties to all four of the states. I have lived in each of the states I studied, and have been affiliated with ASOs in each of the states. The connections I have made in each state proved invaluable, especially because the interviewees were able to relate to me as a fellow resident of each of the states and I built a strong sense of camaraderie with the participants.

As I mentioned previously, I chose to interview ASO personnel (Executive Directors, Prevention Directors, and/or Case Managers) because ASOs are the only organizations that devote 100% of their efforts to AIDS care and prevention education, versus public health departments in which AIDS is just one of the many health concerns in which they focus. I was able to perform nineteen interviews at fourteen ASOs, or 78% of all the ASOs in the 4-state region. There were four ASOs at which I was not able to perform any interviews. At one ASO, the Director quit the day that I was to interview, while another ASO had just hired a new Executive Director the previous week, and therefore they did not know any of the information that I was asking about in the interview. At the third ASO, I had a cancellation and was not able to reschedule with the individual I was to interview. After several letters requesting an interview and follow-up phone calls, I simply was not able to contact anyone at the fourth ASO.

I also conducted twelve interviews with state HIV/AIDS policymakers (State

AIDS Directors, Prevention Directors, Surveillance Directors, Ryan White Titles Directors, etc.), which at the time of the interview process represented 92% of all of the state HIV/AIDS officials in the four states. I only had one state HIV/AIDS policymaker that I was unable to interview due to a cancellation because of a death in their family. I chose to interview state policymakers because, as Price, Everett and Poureslami (1995) found, state HIV/AIDS directors and other state officials involved with public health promotion and prevention education hold a unique position in their ability to influence public policy and financial resource distributions. Also, their perceptions of the epidemic are found to impact decision-making and the health promotion steps that help to control the spread of the disease (Price, Everett & Poureslami 1995). Previous research on AIDS policymakers revealed that, while AIDS educators and senior service organizations are in a power position that could help target older adults with prevention information, they have been slow to respond to these needs (Stombeck & Levy 1998). I wanted to determine if the same were true of HIV/AIDS policymakers in the Midwest, as well as the factors that shape HIV/AIDS policy and education decisions.

I employed a stratified purposeful sampling technique because of the relatively small number of potential participants. This type of sampling highlights the characteristics of particular subgroups of interest in order to facilitate comparisons (Patton 1990). In order to find both the names and contact information for both sets of potential interviewees, I consulted the National Alliance of State and Territorial AIDS Directors (NASTAD 2005) website and the “Local HIV/AIDS service

organizations in the USA” page at AVERT.org (2005). A search of each state’s Department of Health website and a search for “AIDS organizations” confirmed or corrected the contact information I found. After receiving IRB approval from the Human Subjects Committee at the University of Kansas, I sent letters to potential interviewees requesting an in-person interview as part of my dissertation work, and enclosed a self-addressed stamped envelope for the return of an acceptance/denial card as well as potential times and dates for the interview. Communication with the interviewees then took place either by e-mail or phone, and arrangements were made for the interview. I traveled to each interview site to perform the interview, spending approximately one full week in each of the four states to perform as many interviews as possible. I returned to the ASOs and state offices for those who were unable to meet during the designated week.

After describing the study in detail, the participants signed informed consent forms. I asked permission of the participants to be audio-taped with their approval, and none refused. The interviews were semi-structured in nature. I had a number of questions that were demographic in nature, as well as questions that I asked of every one of the interviewees in order to compare answers. Also, I asked several questions that grew out of the individual interviewee’s responses. While I asked additional questions about funding, their organization’s culture, and the relationship between organizations and states, the questions I included in this dissertation project focused on older adults. The interview questions are located below.

- What do you envision are some of the future trends in the infection rate of HIV/AIDS in \_\_\_\_ (State) \_\_\_\_?

- Who do you see as being at-risk for HIV infection?
- Do you agree or disagree with this statement: “I believe that older adults in my community exhibit high-risk behaviors that make them susceptible to contracting HIV.” Please explain your answer.
- What are the activities or behaviors that older adults in your community exhibit that could put them at risk for HIV infection?
- How do you think our culture views older adults and sexuality? Please explain.
- If an older adult walked in off the street, what are three things you would tell them about HIV/AIDS? If the older adult were a gay man, what are three things you would tell him about HIV/AIDS? If the older adult were a woman, what are three things you would tell her about HIV/AIDS?
- What types of health promotion, prevention services, or education for HIV/AIDS do you provide to the older adult population?
- Do you think that sexual enhancing drugs—Viagra, Cialis, Levitra—have any affect on the current HIV/AIDS rate? How so?
- How have physicians in your area reacted to the HIV/AIDS crisis?

Each interview lasted between 45 minutes and 2 ½ hours. I interviewed participants at the ASOs or state offices in private offices or rooms for confidentiality. The interviews took place between July 2<sup>nd</sup> and September 22<sup>nd</sup>, 2006. After completion of the interviews, I typed up my handwritten notes, transcribed the audiotapes of each interview, and reviewed the transcripts for accuracy.

The interviews with the Executive Directors and/or other ASO personnel took place at the actual ASOs, which provided me the opportunity to observe the dynamics of the organization itself. I asked and was provided information on the organizations’ missions, priorities, pamphlets, annual reports, websites information, etc. Within the



interview, participants addressed attitudes, strategies, the inner-workings of the organization, the relationship between the organization and other organizations as well as the state, and other key information that informed this study. The interviews with the state policymakers took place at their offices in the capital city of each state.

I undertook the process of open coding in order to analyze the interviews. Strauss and Corbin (1998) stated that open coding is designed to “open up the text and expose thoughts, ideas, and meanings contained therein” (102). I used several rounds of coding in order to create order out of what Charmaz (1983) refers to as “a mass of confusing, unrelated, accounts” (114), which involved organizing the data in such a fashion that certain themes and patterns began to emerge (Pandit 1996; Glaser & Strauss 1967). I used a constant comparative analysis to identify variations between the interviews both individually and categorically. For example, I looked for patterns across all of the interviews, between the two groups (ASO personnel and state HIV/AIDS policymakers), between the four states, and then between the two groups within each state. Fortunately, strong patterns emerged on all levels, which I interpreted as reaching theoretical saturation.

I then completed a series of more focused coding in which I developed detailed categories that aided in answering specific questions I posed to all of my interviewees. Different sociological explanations and theories emerged from the data—some expected and some I did not anticipate. While my own ideas and definitions were useful when asking the interview questions, they did not take precedence over the interviewee’s experiences and interpretations of the situation

occurring within their own ASO or state. Therefore, I viewed the participants as the experts, and attempted to keep my own interpretation of their responses to a minimum.

### *Organizational Ethnography*

In order to understand how AIDS service organizations operate, I conducted an in-depth organizational ethnography (following the methodology explained by Smith [2005]) of one such organization in the Midwest for a period of nine months. It was relatively simple to gain access to this ASO through volunteer work. Further, the Executive Director of the ASO was particularly interested in drawing attention to the inner-workings of AIDS organizations. I was cognizant of the fact that I did not want to allow my personal ties to this particular ASO to impair my research, but I did want to perform tasks that would benefit the people whose work I was studying. Therefore, I offered my time and services to the ASO, and volunteered to help during various functions such as a fundraising event, an AIDS walk, and at an information booth.

I had volunteered at an AIDS hospice in the past, and therefore was familiar with some of the culture of AIDS service organizations. I wanted to get a better sense of the day-to-day occurrences, and therefore I volunteered one to two times per week, for about three to five hours each time (depending on the day). I was asked to do general office work, such as organizing the databank of past and potential funding sources, answering phones, working on flyers, helping to organize for upcoming events, and other office maintenance work. In addition, I was able to accompany the

Executive Director to various functions, including a state Consortia meeting. This proved to be invaluable, as I was able to get the Executive Director's opinions about the state HIV/AIDS program, the Consortia, and other ASOs in the state.

After each of my days of volunteering, I would write down any notes and observations I made during my time at the ASO. I kept a notepad with me while I volunteered, so I was able to write down direct quotes of what the Executive Director or other personnel said and later typed up all of my notes. For purposes of this dissertation, I coded these notes with a specific focus on anything having to do with aging or older adults.

#### *Consortia Meetings*

As a stipulation of receiving federal money for HIV/AIDS, each region, state, or city that received money are required to form a Consortia that meets on a regular basis, on average about four times a year. The federal money that each state receives in the form of a block grant is a result of The Ryan White Comprehensive AIDS Resources Emergency Act, otherwise known as Ryan White money or the CARE Act. This Act is the only funding source whose sole purpose is to provide funds for people with HIV/AIDS. Further monies are distributed via different governmental programs, such as ADAP (AIDS Drug Assistance Program), HOPWA (Housing for People with AIDS), Medicare, Medicaid, and CDC funds for prevention education. The Consortia is attended by state HIV/AIDS policymakers, staff members from different AIDS service organizations, and consumers. In fact, one of the requirements of the

Consortia is that a specific number of consumers be members in order for the HIV/AIDS community to have a voice in funding decisions.

I contacted the head of each state Consortia and asked permission to attend and observe one of their meetings. Asking permission was required, as most Consortia meetings are closed to the general public. I was granted permission and attended state HIV/AIDS Consortia meetings in each of the four states during the summer of 2006. I took detailed notes on the topics of discussion, the interaction between different Consortia members, and various observations. Again, for purposes of this dissertation, I was listening for specific information related to aging or older adults, though I did take notes for additional research other than the dissertation.

#### *Content Analysis*

In addition to requiring a meeting of an HIV/AIDS Consortia, each state is required to produce a state HIV/AIDS plan as a stipulation of receiving federal money. The state plan contains a snapshot of HIV/AIDS in the particular state, including demographic information about those infected, predictions of infection rates and groups at risk, funding issues, and future areas of concern. I conducted a content analysis of the state HIV/AIDS plans of the four Midwestern states to identify age-related dimensions of the plans, and also conducted a content analysis of four other states with higher rates of older adults among their population and higher incidences of HIV infection and AIDS cases (California, Texas, Florida and New York) as a comparison. I also use secondary sources such as books, articles, media, federal databases, previous research and studies that are both US and state-specific

HIV/AIDS data. The focus of the content analysis and an analysis of secondary sources was on themes of aging and HIV/AIDS, sexuality, and related topics.

### **Research Issues and Challenges**

As with all research, I encountered a few issues and challenges that, to some extent, had an effect on how I conducted my research and reported my findings. Some of these issues surrounded the fact that I was asking sensitive questions about a stigmatized disease. Further, I was asking questions of the Executive Directors and other ASO personnel that directly reflected on their opinions of their state HIV/AIDS policymakers, and therefore the fear of losing funding from the state due to the answers they provided to my questions was a viable possibility. As a result of this situation, I had to take certain measures in order to protect their privacy.

#### *Confidentiality*

Due to the sensitive nature of HIV/AIDS and the relationship between the state policymakers and the AIDS service organizations, I chose not to directly disclose the four states in which the interviews and Organizational ethnography take place. When it is necessary to describe the particular state I'm referring to, I refer to the state as "State A", "State B", "State C", and "State D." Additionally, I renamed the ASO in which I conducted an Organizational ethnography as "Positive Action." The names of the individuals whom I interviewed are also kept confidential. They are only referred to by their general job title (i.e., Executive Director, Prevention Director, etc.) and the state in which they reside. It is especially important that the interviewees felt confident that their identities would be protected, especially in light

of the aforementioned funding issues and program decisions.

### *Sampling*

While many different public health institutions (public health departments, university health centers, and health clinics, for example) may have some type of outreach program that addresses HIV/AIDS education, or they may offer HIV tests, ASOs are unique organizations. As mentioned in earlier in this chapter, ASOs are the only organizations that focus specifically and solely on the issue of HIV/AIDS, both in terms of providing social services to those who are infected, testing to the general public, and prevention education outreach. Therefore, I knew that I would like to recruit my sample from ASOs. Additionally, I chose to sample state HIV/AIDS policymakers because they are recipients of federal monies used for HIV/AIDS. State HIV/AIDS policymakers are also heavily involved in the Consortia, and tend to have a large role in how issues related to HIV/AIDS are handled in their respective states.

Because of the relative rarity of ASOs—in the Midwest, there are only a handful of ASOs in each state—and the small amount of state policymakers in the area of HIV/AIDS, I decided to use a stratified purposeful sampling technique. In other words, the individuals in my sample were conspicuous by their rarity. In a sense, I was really performing expert sampling by assembling a sample of people with demonstrable experience and expertise in HIV/AIDS. On the one hand, it is a strength of my dissertation research that I was able to exhaust my sample pool and truly capture the thoughts and opinions of those who perform HIV/AIDS prevention

education and policymaking in each state. On the other hand, I did not have as much variation among my respondents as I would have liked. This was a result of the fact that many decisions about funding and prevention education are made by the Consortia, as well as at the state-level. Further, due to time, financial, and location constraints, I chose not to interview older adults themselves at this point in my research. I'm hoping to take my findings from this dissertation and expand it by including interviews with older adults at some point in the future.

### *Opinions*

Another research issue that I encountered in this dissertation was the fact that I often had to rely on my interviewees' opinions as answers to my interview questions. In all fairness, though my interviewees are "experts" in the sense that they are either Executive Directors or personnel at ASOs, or they are involved in state-level HIV/AIDS policy, I was, in some cases, eliciting their opinions and not hard and proven facts. While they were certainly able to provide me with accurate numbers of clients served, monies received, and other fact-related answers, some of their answers to my other interview questions began with the phrase, "This is only my opinion, but..." However, the fact that I did not receive an extreme amount of variation across interviews is a plus in this instance. This indicated to me that, opinions or not, these answers held some validity if a large number of my interviewees were giving the same answers.

### *Subjectivity and Bias*

As the narrator and person who is framing the findings of this research, I have

both subjectivity and bias, and the way that I report my findings and provide analysis could hold some semblance of a bias. As an outside observer, I initially anticipated that HIV/AIDS organizations were slow to observe the emergence of HIV/AIDS in the older population because of existing stereotypes about older adults and sexuality: these adults were simply not at risk for HIV infection because they do not have sex or participate in other ‘immoral’ activities that would put them at risk. I suspected that HIV/AIDS organizations purposefully defined at-risk populations as young people, homosexuals, and drug users while virtually ignoring the increasing risk that older adults face. I realized that perhaps my deductive reasoning was a result of my own bias (and reading what was available in the literature), and that I needed to have an open mind while collecting data. In other words, I needed to entertain the idea that there might be another reason why there existed the possibility that older adults were being left out of HIV/AIDS prevention education.

My research question expanded to include possible social factors that explain why older adults might be excluded from HIV/AIDS prevention education versus simply assuming that it was just about the existing sexual scripts concerning older adults. I also began to see certain patterns emerge as I was conducting my interviews, patterns that I had not anticipated when I created my interview script. From that point, I began to expand upon questions concerning local physicians’ reactions to the HIV/AIDS epidemic, the local community’s reaction to the epidemic, and how the local and state governments were influencing how HIV/AIDS was addressed in each of the communities in which I visited. I was seeking as many perspectives as



possible, and added new topics to the interviews. I revisited the literature, looking for other research that would concur or diverge from what I was hearing in my interviews about local influences that may be impacting prevention education.

The following chapters are the result of the interviews I conducted, as well as the data I collected through the methodologies and procedures described in this chapter. The methodologies and procedures I utilized for this dissertation project, as well as the theoretical frameworks that helped to guide my initial research, assisted me in answering the questions posed in Chapter One. In Chapter Four, I provide a description of the social organization of the HIV/AIDS epidemic in the Midwest. Chapter Five includes the responses to the interview questions I asked of my interviewees, and in Chapter Six I analyze and discuss these responses in order to answer the question of whether or not older adults in the Midwest are left out of HIV/AIDS prevention education policy.

## **Chapter 4: The Social Organization of HIV/AIDS in the Midwest**

As was discussed in Chapter One, the HIV/AIDS epidemic is unusual and unique compared to other epidemics and diseases. While there is an apparent pyramid-like system of distributing federal funding, there is no national organization that oversees all HIV/AIDS organizations in the U.S. (such as the system that exists with other diseases described in Chapter One). Further, there is no protocol to how each ASO organization should function or the clientele they should try and reach. This chapter is a synthesis of my observations about how each organizational level of the HIV/AIDS epidemic in the Midwest functions, and how the social organization of HIV/AIDS may help to highlight the possibility that older adults are left out of prevention education.

### *State Policymakers*

Each of the states' HIV/AIDS divisions is housed under a state department, such as the state Department of Health or Department of Social Services. Some of the HIV/AIDS programs are grouped in with other diseases, including Hepatitis, Sexually Transmitted Diseases, and Tuberculosis. I interviewed each of the four states' Executive Directors (sometimes called Program Managers), and other state policymakers, including Prevention Coordinators, Ryan White and AIDS Drug Assistance Program (ADAP) Coordinators, and HIV Surveillance Program Managers. While overall I interviewed more women than men, three out of the four Executive Directors were males. Only one of the Executive Directors had previously worked at

an ASO.

The job of the state policymakers is to coordinate each of the respective programs that they run, including handling the Ryan White Care Act funds that are distributed to each state in the form of a block grant. These funds are used for the care of individuals who are infected with HIV or have AIDS, and are distributed to ASOs and community Departments of Public Health. Other government funds that are provided to states include ADAP programs (which help provide HIV/AIDS drugs to low-income individuals), HOPWA (Housing for Persons with AIDS) funds, and CDC funds for prevention education. Each state must apply for each type of funding from each of the government agencies who provide the funds on a yearly basis, and it is a time-consuming process that involves meticulous tracking of numbers of those tested and infected individuals. In addition, each state policymaker develops a budget, decides who is eligible for benefits from each program, and tracks the money spent and the clients using each program.

While recommendations for funding distribution and priority groups are established at Consortia meetings, the state policymakers have the final authority over who receives what amount of funding. For example, funding cuts from the federal government resulted in one ADAP Coordinator from one of the four Midwestern states deciding to close the program for a year and not provide any more HIV/AIDS drugs to low-income individuals. It is not uncommon for the state policymakers to close different support programs, as states have faced flat-funding (the best case scenario) or severe reductions (the worst case scenario) over the last several years.

For example, funds from the CDC for prevention education have dwindled to almost nothing for three of the states, and prevention education must now come out of the ASOs' own pockets.

The fact that only one of the Executive Directors had any experience working at an ASO may be at the detriment of the ASOs at the community level. After some of the interviews with state policymakers, I was left with the impression that perhaps the state policymakers were more concerned with budgetary issues and numbers than with people who were actually infected. This is, admittedly, part of their job; however, I question whether a disconnect with the day-to-day inner-workings of the ASOs and direct contact with clients has had some influence on the funding and budgetary decisions being trickled down to the ASOs. For example, it appeared rather unproblematic for some of the state policymakers to close or discuss the possibility of shutting down social programs that could be devastating to clients with HIV/AIDS. Further, if the state policymakers did not think that older adults were at risk for HIV/AIDS based on aggregate data, they would most certainly have the bureaucratic power to dissuade any ASO personnel from addressing this specific population.

#### *Consortia Meetings*

As a requirement to receive Ryan White CARE Act funds, each state must hold a Consortia meeting, sometimes called a Community Planning Group, in order to produce a state HIV/AIDS comprehensive plan. Each Consortium group is a combination of state policymakers, ASO personnel, personnel from Public Health

Departments, and members of the community who have the disease. The goal of the Consortia is to provide recommendations to the state (in the form of the above-mentioned state HIV/AIDS comprehensive plan) concerning the determination of risk groups, budgetary needs, prevention and intervention services, and other structural suggestions that they would like the state policymakers to consider. There does not seem to be a standard as to how the Consortia is constructed in each state; some states meet as one state-wide Consortium group, while other states divide up the state into different regions and have several Consortia.

While there is no apparent protocol or strict standard provided by the federal government apart from requiring a Consortium in exchange for Ryan White funding, each Consortium meeting I attended (one in each of the four Midwestern states) functioned in a very bureaucratic and organized manner. Meetings were called to order and attendance was taken, as each Consortium member was required to attend a certain number of meetings or face suspension from the Consortium. There were several different committees in which the members of the Consortium participated, and each committee provided an update of activities and budgetary concerns. Each state Consortium group followed a similar bureaucratic pattern with dialogue about funding and budgets being at the forefront of the discussion. At one Consortium meeting in particular, there was a half-hour period of time in which the discussion centered on reimbursement of costs for those who traveled to the meeting. As one ASO director confided to me, "These Consortia are always like this. They are more concerned with reimbursement than any real issues."

While I understood that funding and budget concerns were going to be a focal point of each Consortium, I was not prepared for the level of bureaucratic and organizational discussion and the lack of any conversations about HIV/AIDS itself. Any disease or social issue could have been substituted for HIV/AIDS in the course of the discussions throughout the Consortia meetings. In a sense, this made me realize that, while there is no formal protocol or national parent organization overseeing how these Consortia should be conducted, each state made an effort to run their Consortium meeting in a very organized and bureaucratic manner as they would with any social issue or disease. Perhaps this was a conscious decision on the part of each group in order for them to be taken seriously by state legislatures and federal funding sources.

The rapport within some of the Consortium groups did surprise me a bit. In two of the states, it became apparent that the relationship between different members of the Consortia—particularly between state policymakers and ASO personnel—was adversarial in nature. I sensed a bit of mistrust on behalf of certain vocal members of different ASOs about how much of the states' overall HIV/AIDS budgets go towards paying the salaries of the state policymakers, especially in the wake of budget rescissions for each of the ASOs. This mistrust and in-fighting within the Consortium group was not uncommon, as an ASO director told me that “A lot of CPG (Community Planning Groups/Consortia Groups) groups are dysfunctional.”

I was a bit naïve to believe that every member of the Consortia groups would be cooperative simply because they all had a common goal, helping those infected

and impacted by the HIV/AIDS epidemic. What I failed to take into consideration was the fact that these Consortia were run similarly to other organizational and bureaucratic structures, and therefore faced similar problems as those structures. For example, two of the four Midwestern states had problems concerning paperwork and number tracking. In one state, the implementation of new acuity scale paperwork was well-received by the state policymakers who found it made it easier to track numbers. However, ASO personnel found it difficult to implement because of issues of interpretation, time, and the fact that it was more paperwork for them to fill out. Another state faced a similar issue, with state policymakers requiring that ASO personnel fill out HIV/AIDS surveillance numbers on paper instead of entering them into a computer. The state policymakers believed that everyone was “messing up” the statistics, therefore requiring the ASOs to return to a paper trail versus computer entry. This did not sit well with ASO personnel, who argued that they already had more than enough work to do without adding this extra burden.

Overall, my observations at the four Midwestern state Consortia meetings was that each state is struggling with bureaucratic constraints and limited resources—both money and people. Responsibility is placed heavily on the shoulders of these individuals (mainly ASO personnel) to make sure that their clients do not fall through the cracks, but this must be done on limited funding and manpower. Short staffing at the state level (not replacing state policymakers whose jobs have been vacated) results in a lag in organizational work, as well as in disbursing money to the organizations; however, this short staffing is the only action that can be taken in order

to keep budget cuts from continuously affecting the ASOs in a detrimental way. As one state policymaker (who chose to absorb another position into their own rather than spend the money to hire someone new) said, “We’d rather have money go to services than staff if we can.”

I was particularly interested in discussion about prevention funding, as the focus of my dissertation is on prevention education for older adults in the Midwest. Each state suffered budget cuts from the previous year (some have faced this trend for several years), and therefore programs and services were either cut or eliminated. Prevention funding was one of the programs that was either drastically cut or eliminated in each of the states, making it difficult for any of the states to expand their focus to other populations at risk for infection besides the original groups and those deemed “high-risk.” As one state policymaker explained at the Consortium meeting,

There aren’t enough dollars for HIV prevention, and there are likely to be fewer in the future. HIV prevention efforts have to be focused on people most at risk. The question that all groups need to answer is: How can we prevent the most infections in our community?

This was not a unique perspective, as another state policymaker told the Consortium that there was “no money for [us] to go out” and provide prevention education. When there is a bit of money set aside for prevention education or testing, it is usually targeted for specific groups; one state showed evidence of targeted testing in which women of color were tested and received prevention education, but White women were not tested, even though they were all in the same geographical area. There is simply little or no money coming down from the federal government ear-



marked for prevention education for the masses, and it appears that states are only allocated prevention education funds for certain groups—those deemed as being high-risk by the government/CDC. The request by ASO personnel for more prevention education funds is going unfulfilled as state policymakers are re-appropriating funds to cover other programs that have been cut or eliminated due to overall budget cuts.

#### *ASOs*

Out of all of the “players” in the HIV/AIDS organizational pyramid, ASOs (AIDS service organizations) are arguably the most critically important in the fight against the epidemic. As was mentioned in Chapter One, ASOs are ground-level, community-based organizations created by gay men in the 1980s as a safe haven for those who were infected and dying. As the disease became less fatal and more chronic in nature, ASOs became a different animal. They moved away from being a hospice-type organization to becoming a resource-type organization. ASOs provide counseling and testing services, case management services for HIV positive people or persons with AIDS (PWAs), and prevention education in the community in which they are located. They provide these direct services, as well as palliative care, and prevention education to a wide range of different populations (Barton-Villagrana, Bedney & Miller 2002).

Financially, ASOs used to be supported almost exclusively by wealthy gay donors and volunteers. However, the exorbitant cost of caring for infected individuals and offering prevention education and testing became a heavy burden, so ASOs now rely heavily on federal and state money to support their organization.

This money comes in the form of the Ryan White CARE Act grant, CDC funds, and other governmental sources, state matching funds (where available), private foundation monies, and fundraising efforts.

After receiving the recommendations of the state HIV/AIDS Consortia via an state HIV/AIDS comprehensive plan, state policymakers look at their budgets and decide how best to allocate funds to different ASOs and public health departments. Something that is a unique aspect of the way in which HIV/AIDS is organized is the sense of competition for money among different ASOs. Because there is no “parent” or national HIV/AIDS organization, there is no standard as to how to allocate funds to each organization. Therefore, each ASO acts as a partner as a member of the Consortia, yet acts independently when it comes to competing for allocated dollars. This does have the tendency to cause a bit of friction between some ASOs, as one Executive Director explained.

So what this means for all of our community-based organizations is that we are struggling more and more for foundation dollars and private dollars, and the competition now is that—which is how it always is for not-for-profit organizations—is that you are happy when somebody gets a grant, but there’s that little “devil” piece of your mind that says “Damn it, why didn’t we consider sending to that?” What it does is further fragment the service delivery, further create more complication and competition, and make it more difficult for organizations that don’t have the staff.

In some states, state legislatures will match certain federal funds (Ryan White CARE Act funds, for example, are supposed to be matched by each state), which helps to increase the pot of money for HIV/AIDS. However, this does not occur in every state, and some states are at more of a financial disadvantage than others. One of the states in this dissertation, for example, did not submit an application for a

major federal funding source, and therefore lost out on a substantial amount of money which would have been distributed to ASOs and other community organizations. As government funds continue to dwindle, ASOs are relying heavily on fund-raising skills and diversifying their funding portfolios, or are forced to cut programs such as testing or prevention education.

Several ASOs I visited were forced to cut important core programs. For example, there were a few ASOs that had to stop offering HIV testing because they were not receiving any funds to buy the tests or administer the tests. At one of the ASOs, the Executive Director explained,

One of the services that is at risk here at \*\*\*\*\* right now is our HIV counseling and testing program. We receive zero dollars from the state to provide this service. However, they do provide the testing materials. But because we are on such a limited budget with the need for cutting back, counseling and testing is something that ends up going away. We are closing it for the summer and we will maybe re-evaluate it from there.

Further, a majority of the ASOs were forced to stop offering prevention education because federal funds had been cut so much that they would not be able to cover any prevention education costs. As one ASO Executive Director stated, “We don’t have the resources to be able to cover them (citizens in their state) like we should. We just don’t have the resources to do that. The need is there but we just can’t.” At an ASO in a rural area of a state, a Case Manager who also acts as an Executive Director of the ASO provides prevention education at night when the individual is off the clock, because there is no prevention education money in the budget.

ASOs rely greatly on volunteers to keep their organizations running, which is

steeped in the tradition of being primarily volunteer-based organizations. Every one of the ASOs I visited while collecting data for my dissertation had a volunteer-base that outnumbered paid staff. However, the practice of having volunteers run the organization is not as strong as it was in the early days of the epidemic. Many gay men who once ran the organizations have either died of AIDS themselves or have relinquished control of the organizations to paid staff. Along with gay men being noticeably absent from a number of the ASOs, the number of volunteers at each ASO had dwindled considerably from the early days of the epidemic. Several of the ASO personnel I interviewed commented that they were not recruiting new volunteers like they used to, and that their core volunteer-base were long-term volunteers who had been there since the early days of each ASO. HIV/AIDS is simply not on the radar like it used to be, and ASOs are suffering because of it.

Funding cuts resulted in some ASOs having to cut paid staff and rely even more on volunteer workers. One ASO Executive Director spoke candidly about having to lay off staff because of funding cuts from the state, saying “We cannot function as an agency if we cannot staff it. We can’t staff it if we don’t have some money to staff it.” This was not an uncommon phenomenon among the respondents. A Regional Case Manager who also serves as an Executive Director of a branch of an ASO in one state was forced to let go of staff and instead rely on a core group of ten volunteers to keep the ASO afloat.

While volunteers were once the foundation of many ASOs, individuals are not volunteering as much as they once did. The problem of a dwindling volunteer-base is

especially detrimental to smaller ASOs in states in which ASOs are few and far between. For example, an ASO in a rural area of one of the Midwestern states serves an area that spans 350 miles between clients; only one paid staff and one Volunteer Coordinator run this particular ASO. It is extremely difficult for these two individuals to run their ASO and serve clients who are so vastly spread out. This ASO is not being provided with additional funds by the state, and their volunteer-base is quite small and unable to provide increased support, such as driving clients to appointments or driving out to rural areas to provide prevention education. This is a problem that appears to be unique to ASOs in rural areas, as those ASOs I visited in urban areas appeared to have a larger volunteer-base and less transportation issues.

In general, all of the ASOs I visited functioned in a similar fashion. They each provided services (case management, testing, prevention education, etc.) of some sort, though several had to either reduce or cut their programs due to budget rescissions. Each acted as independent organizations except for one state's ASOs, which were all connected and had different branches in different parts of the state. The physical structure of the ASOs ranged from a large, spacious, well-decorated loft-style building in a medium-sized city to a one-room office area in a small town. A majority of the ASOs were located in structures that had a few offices, a front desk, and a meeting area that varied in size. Some ASOs were located in areas around other businesses, while a large number of ASOs were situated in poor areas of town with higher crime rates.

Something that I witnessed over the course of my data gathering was a trend

among some of the ASOs who were experiencing the effects of continued discrimination against people with HIV/AIDS. Several of the ASOs were in the process of either removing their names from the front of the door or building, or even changing their ASO's name to something that was vague enough so as not to be associated with HIV/AIDS. This was surprising to me, as I believed that the stigma associated with HIV/AIDS was not so extremely detrimental that even walking into a building with the word "AIDS" on the front door would elicit negative responses from communities. I was naïve to the fact that, while it might not be extremely stigmatizing to walk into an ASO in a large city, that it would be in a smaller city or small town. An ASO Executive Director commented that, "We do have people that still won't come to our office, people who are in our case management services but we have to send our case managers out to meet them somewhere else." One ASO in a small town had a difficult time finding a mail-person who would walk into the ASO to deliver mail. At another ASO, the Executive Director had negative "Letters to the Editor" written about them in the local paper, and felt attacked via messages left on their answering machine and taped to the door of the ASO. In my opinion, these were issues that I thought had been dealt with in the 1980s and 1990s; I did not expect to be hearing about them in the year 2006.

Another reason given as to why some ASOs were changing their names was because of pressure from funding sources. A few ASO personnel commented that some of their funders did not want their checks to be made out to an organization with the word "AIDS" in the name. Fearing that they would lose this desperately needed

money, a few of the organizations decided to transition their names to more neutral-sounding titles. The consensus was that their funders would not be embarrassed to have their names listed on a donor poster of an organization named “The Project” versus an organization with the word “AIDS” in its title.

In addition to all of these financial strains and organizational constraints, the relationship between the ASOs and the state policymakers further exacerbated these problems. In two of the Midwestern states, some of the ASOs had somewhat contentious relationships with the state policymakers. While it was apparent that both ASO personnel and state policymakers were focused on the same goal of helping those who were infected with HIV/AIDS, as well as educating those who were not infected, each side appeared to have a different way of looking at the same issue. For example, an ASO Executive Director in one of the Midwestern states felt that their relationship with the state policymakers was “strained,” and that they had repeatedly been told that they had to cut their ASO budget. The Executive Director said that they told the state policymakers that

“I’ve got a real struggle here trying to do what you [the state policymakers] are asking me.” And they [the state policymakers] say, “Well, don’t you want to do it anymore? Because we can take those dollars and put them someplace else.”

This threat of rescinding allocated funds if demands are not met also occurred in another state. An ASO Executive Director from this state explained that “They [state policymakers] are constantly, literally, threatening ‘If you don’t do this, then we are going to pull your contract.’” The state HIV/AIDS Director explained that they do, in fact, threaten to pull funds because they were acting as stewards of the

fundings. According to the HIV/AIDS Director, “\*\*\*\*\* [the ASO] will either come out of this or they will die. There’s not going to be an in-between on this one.”

When looking at how HIV/AIDS is socially organized in the Midwest, a few issues stand out. First, HIV/AIDS is socially organized much like other social issues and diseases without having a “parent” or national organization guiding the organization process. As a result, each level experiences the same bureaucratic issues that other organizations face, such as strained relationships between different groups and competition for funding. Second, the funding cuts from the federal level down has resulted in each level—the state policymakers, Consortia groups, and ASOs—having to do more with less money and manpower. The consequence of these cuts is that there have been services and programs that have either been reduced or disbanded, including prevention education and testing/counseling services. Third, there is little to no money left over to provide HIV/AIDS prevention education to older adults and other groups who are off the risk radar of the federal government. If older adults are left out of HIV/AIDS prevention education in the Midwest, it may very well be a result of these structural and organizational issues.

In the following chapter, I provide the responses to the interview questions I asked of my interviewees. I look to see if trends exist among state policymakers and ASO personnel in their responses concerning HIV/AIDS in the Midwest. Chapter Six includes an analysis and discussion of these responses in order to decide if older adults in the Midwest are left out of HIV/AIDS prevention education policy.



## **Chapter 5: Older Adults' Inclusion in HIV/AIDS Prevention Education**

There has been an increasing volume of research (ACRIA 2006; Inelmen, Gasparini & Enzi 2005; Levy-Dweck 2005; Altschuler, Katz & Tynan 2004; Falvo & Norman 2004; and Coon, Lipman & Ory 2003, just to name a few) over the last few years that stress the growing importance of providing HIV/AIDS prevention education to older adults. Based on the numbers and proportion of new infections and diagnoses among the older adult population, it is apparent that older adults remain sexually active, still exhibit past risk behaviors that may be putting them at risk for infection, and continue to lack accurate information about HIV/AIDS (Altschuler, Katz & Tynan 2004). Despite numerous warning signs, research shows that there continues to be a general lack of HIV/AIDS prevention literature aimed at older adults (Orel, Wright & Wagner 2004). In order to decipher whether this was true in the Midwest, and if so, the reasons why older adults were excluded from HIV/AIDS prevention education, I used the qualitative methodologies described in Chapter Three to examine the level of older adults' inclusion in HIV/AIDS prevention education.

In this chapter, I present the answers to the questions concerning older adults and HIV/AIDS that I posed in my qualitative interviews with state HIV/AIDS policymakers and ASO Executive Directors or personnel. I also disclose any age-related data I uncovered during the process of coding my notes from the organizational ethnography I conducted at an ASO, the notes I took at my attendance at the four state HIV/AIDS Consortia meetings, and the age-specific data I coded in

the four Midwestern states' HIV/AIDS plans, as well as those of four comparison states. This chapter is an accumulation of the data I collected that is specifically age-related.

### **Interviews**

As previously mentioned in Chapter Three, I was able to perform nineteen interviews at fourteen ASOs (78% of all the ASOs in the four state Midwestern region), and twelve interviews with state HIV/AIDS policymakers (92% of all of the state HIV/AIDS officials in the four states). I had a set list of questions which I asked every interviewee, ranging from questions concerning funding issues, the inner-workings of the organizations or state offices, the relationship between the state policymakers and the ASOs, barriers and reactions to the HIV/AIDS crisis from the communities and local/state governments, and general questions about the HIV/AIDS crisis in their local communities and nationwide. The data collected from these questions will be used in future research. After asking a set list of questions, I let the interviewee talk about any areas of HIV/AIDS they desired.

Questions pertaining specifically to older adults were asked and are the focus of this research. I asked six questions that were exclusively about older adults; further, the answers to two other questions not specifically related to older adults were answered by some in such a way that they also focused on age-related issues. Keeping my research questions and theoretical frameworks in mind, I grouped the answers to the questions I posed to the interviewees into three categories: High-Risk Behaviors, Sexual Scripts, and Prevention Education. The following are a synopsis

of the answers, as well as the themes and trends that emerged from the respondents' answers. As a reminder, for purposes of confidentiality, I refer to the four states as "State A", "State B", "State C", and "State D." For the following answers, I also state whether the answer came from a state policymaker or from ASO personnel. I separate the responses from state policymakers and ASO personnel in order to see if there are differences in responses from the two groups. Because ASO personnel are at the "ground level", so to speak, and have direct contact with members of their respective communities, I anticipated that there may have been differences in their responses versus those of state policymakers who have less community involvement.

### ***High-Risk Behaviors***

I asked three questions that were specifically about the high-risk behaviors that older adults may or may not be exhibiting that put them at risk for HIV/AIDS. The first question was asked in the following manner: **Do you agree or disagree with this statement: "I believe that older adults in my community exhibit high-risk behaviors that make them susceptible to contracting HIV."** The overall consensus among both state policymakers and ASO personnel was that older adults do exhibit high-risk behaviors that make them susceptible to contracting the virus. Twelve state policymakers answered this question, with nine saying "yes", older adults do exhibit high-risk behaviors. One state policymaker said no, that they did not think older adults exhibited behaviors that could put them at risk for contracting HIV. One policymaker said that the answer was yes and no, that some older adults may exhibit behaviors, but others did not. When pressed, the state policymaker said

that older adults who were gay men or IV drug users were the ones who exhibited high-risk behaviors, and that all other adults did not. Finally, one policymaker said they did not know if older adults exhibited high-risk behaviors.

When asked the same question, eighteen ASO personnel said that older adults do exhibit high-risk behaviors that make them susceptible to contracting HIV. Only one employee at an ASO said they were not sure if older adults exhibit high-risk behaviors or not. These findings are listed below in Table 5.1 (state policymakers) and Table 5.2 (ASO personnel).

**Table 5.1: Older Adults Exhibit High-Risk Behaviors That Make Them Susceptible to HIV Infection, State Policymakers**

<b>Exhibit Behaviors</b>	<b>State A Policymakers</b>	<b>State B Policymakers</b>	<b>State C Policymakers</b>	<b>State D Policymakers</b>	<b>Total</b>
<b>Yes</b>	2	4	2	1	9
<b>Yes/No</b>				1	1
<b>No</b>	1				1
<b>Don't Know</b>			1		1

**Table 5.2: Older Adults Exhibit High-Risk Behaviors That Make Them Susceptible to HIV Infection, ASO Personnel**

<b>Exhibit Behaviors</b>	<b>State A Personnel</b>	<b>State B Personnel</b>	<b>State C Personnel</b>	<b>State D Personnel</b>	<b>Total</b>
<b>Yes</b>	4	4	4	6	18
<b>Yes/No</b>					
<b>No</b>					
<b>Don't Know</b>		1			1

Based on the answers provided to this question, both state policymakers and ASO personnel tend to believe that older adults do exhibit high-risk behaviors that make them susceptible to HIV infection. However, a few state policymakers did not necessarily believe older adults exhibit high-risk behaviors, and one did not know.

One policymaker explained why their answer was yes and no.

If I look at the community as (State D), I would say it's a very mixed agree and disagree. I do think that there are some very solid hard-core peer-valued Midwestern people throughout the states particularly in older populations, they really don't. I think there are certainly, though, plenty that are exhibiting high risk behaviors in other parts of the state too. It's a mixed bag. In \*\*\*\*\* I certainly know that yes, there are plenty high risk behaviors going on in older adults. (State D Policymaker)

Another policymaker from State C pointed out that the reason they agree that older adults exhibit high-risk behaviors is that they “don't know that they [older adults] are any different than any other group” when it comes to exhibiting certain types of behaviors.

Nearly all of the ASO personnel believed older adults did exhibit high-risk behaviors, which could be a result of the fact that they work within the community and are familiar with the high-risk behaviors that are being exhibited due to this proximity to community members. As one ASO Executive Director from State C explained, “Yes, I agree, and I don't think it is just [in] my community.” Several ASO personnel pointed out that these high-risk behaviors do not necessarily have to be dangerous; they could simply be a behavior that most people will partake of at some point that could put them at risk. An ASO Executive Director from State D said, “I think that everybody likes to have sex, so I'd say yes, they are at risk.”

The second question I asked about the high-risk behaviors that older adults may or may not be exhibiting that put them at risk for HIV/AIDS was: **What are the activities or behaviors that older adults in your community exhibit that could put them at risk for HIV infection?** The answers I received were not mutually

exclusive, and I was given anywhere between one and several answers from each respondent. I grouped the answers into eight different categories: 1) Exhibiting the same behaviors as other groups, or just having sex; 2) Dating, dating after divorce, or infidelity; 3) Drug abuse or IV drug use; 4) Men who have sex with men (MSM); 5) Dangerous sex behaviors, which include (according to the respondents) being a “swinger” or attending sex parties, promiscuous sex/multiple partners, internet sex, or being a “bugchaser” (intentionally seeking to be infected); 6) No testing; 7) Sexual scripts, which include not worrying about pregnancy because women are post-menopausal, growing up in an era where condoms were not used, not asking about sexual history, and not discussing safe sex; and 8) Not using protection. Table 5.3 below lists the number of times state policymakers and ASO personnel stated these particular behaviors that put older adults at risk for HIV infection.

**Table 5.3: Exhibited Behaviors that Put Older Adults at Risk for HIV Infection, Policymakers and ASO Personnel Responses**

<b>Exhibited Behaviors that Put Older Adults at Risk for HIV Infection</b>	<b>State Policymakers</b>	<b>ASO Personnel</b>
<b>Same Behaviors As Other Groups/Sex</b>	1	2
<b>Dating/Divorce/Infidelity</b>	2	9
<b>Drug Abuse/IV Drug Use</b>	2	5
<b>MSM</b>	1	2
<b>Dangerous Sex</b>	6	3
<b>No Testing</b>	1	0
<b>Sexual Scripts</b>	3	17
<b>No Protection</b>	2	5

*Same as Other Groups.* One policymaker and two ASO personnel stated that the behaviors exhibited by older adults that put them at risk are the same as other groups, especially engaging in sexual activity. As one ASO Executive Director from State B explained, “They are having sex. People think that you have to do some weird, unique thing to be at risk. No, you just have to have sex!” A state policymaker from State C provided further explanation:

I guess the thought is why would we think that older adults would be different than other groups of people? They date, they have substance abuse problems, they have housing problems, they have mental illness...all of these factors that contribute to people acquiring HIV are the same factors in older adults.

*Dating.* Similarly, two policymakers and nine ASO personnel said that dating, especially after divorce, was a risk behavior that older adults exhibit that may put them at risk for HIV infection. Once I probed the question a bit further, it became apparent that it was not necessarily dating, per say, which put them at risk, but was the fact that older adults were never socialized to think about safe sex (i.e., sexual scripts). The result was that older adults were entering the dating scene again without proper socialization concerning the importance of safe sex at any age. The following quote from an ASO Executive Director from State D describes this scenario.

I think people who are maybe going through separations or going through life changes, they are not used to thinking in the safer sex category because when we were in our 20s, this didn't exist. Or we didn't know about it, and so if you've been married for 15 or 20 years or been in a relationship for 15 or 20 years and are just getting back out there, it's not something that is going to be at the forefront of your mind. (State D ASO Executive Director)

A few ASO policymakers also mentioned that “dating” also incorporated husbands who are cheating on their wives either with other women, but more likely

with other men—a phenomenon often referred to as being on the “down low.” An ASO Executive Director from State B explained that this occurs regularly in their community, and is the main transmission route for their female HIV population over the age of 45.

Let me tell you, I regularly frighten married women. I don't mean to but...when you tell them, look...30% of our [HIV-infected] population is women, and 80% of those women were infected by men who [were] monogamous partner[s]. Guess what? That was a man! That was a husband or a boyfriend. So it's an issue. People have a false idea that marriage protects them from all sorts of things. (State B ASO Executive Director)

*Drug Use.* Drug use/abuse or IV drug use was listed by two state policymakers and five ASO personnel as being a risk behavior that they view some older adults exhibiting. As one ASO Executive Director from State D said, “Being 59 don't mean you don't use meth!” An example of just how many older adults use drugs came from one of the ASOs in the four-state Midwestern region which runs an underground needle-exchange program out of their location. In one year's time, the ASO's underground needle-exchange program exchanged 37,000 needles. According to the Executive Director, “The people that we see on the program are not young people...we are talking about people in their 40s and 50s. These are people who have been using for years.”

Drug use as a risk behavior that older adults exhibit, thereby placing them at risk for HIV infection is not necessarily the use of illegal drugs. As a state policymaker from State B stated, it could be a matter of sharing needles that puts older adults at risk for contracting HIV.



Unprotected sex and drug use, needle sharing. It doesn't have to be drugs, it doesn't have to be illegal drugs. It can be anything in which you are going to share paraphernalia with someone who might be infected. We had a number of cases where an individual would get needles from an older family member who is diabetic and giving themselves insulin because those are good needles. The philosophy among some of these folks was "Aren't I safer using Grandma's discarded needle than I am sharing with a bunch of friends?" Yeah, you are right, but as times got tighter and tighter, Grandma might be using hers two or three times. There was a lot of potential there. (State Policymaker State B)

*Dangerous Sex Behaviors.* Six state policymakers and three ASO personnel stated that dangerous sex behaviors that some older adults exhibit may be putting them at risk for HIV infection. The behaviors mentioned include being swingers or attending sex parties, having promiscuous sex or having multiple partners at one time, finding sex on the Internet, and being a bugchaser, which is the term used to describe an individual who seeks to be intentionally infected by someone who is HIV-positive. Several respondents claimed that they knew many members of their respective communities who were exhibiting these behaviors, and that it was just a matter of time before these groups would experience an outbreak of HIV or another sexually transmitted disease.

A few state policymakers commented that exhibiting dangerous sexual behaviors could be a product of being risk takers as adolescents and not modifying behaviors as they aged. As a state policymaker from State B stated,

Some folks survive their youth and modify their behavior, but we are talking about human beings. Some people still may exhibit behaviors and risk taking. Sometimes the longer you live and you haven't had things happen to you...if you live a long time and think well nothing has really negatively impacted me, so you do the same risks. (State Policymaker State B)

Another state policymaker from State D believed that it was specifically the Baby

Boomer generation who were at risk because they grew up exhibiting potentially dangerous sexual behaviors and did not learn to modify them or protect themselves against the risk of HIV infection.

Sex, drugs and rock and roll are all part of the life, particularly with Baby Boomers. They've grown up in a time, from the time of their adolescence, that was the 50s and 60s, and we all remember what was going on with the freedom of flow and things then. That's a part of their life that has just continued on. I know what it's been like and that's not going to change. They are not hearing the message at all. They, particularly heterosexual baby boomers, are just not going to hear the message and aren't seeing it as them. (State Policymaker State D)

*Sexual Scripts.* Sexual scripts, which serve as a type of social regulation of sexual behavior via set standards and constructed norms, were seen as a possible risk that may increase older adults' chances for contracting HIV infection. While this was mentioned by only three state policymakers, seventeen ASO personnel's statements were coded as referring to the sexual scripts of older adults as being potential risk behaviors. Adhering to sexual scripts was, by far, seen as the biggest risk behavior that older adults exhibit. These sexual scripts which older adults adhere to included: not worrying about pregnancy due to menopause, and therefore not using protection; not asking about sexual history; and not discussing safe sex with partners. One ASO Executive Director from State C explained how older adults did not grow up in an era where talking about safe sex was a priority.

You are no longer at risk for pregnancy, you didn't grow up in era when condom use was common, you're certainly not going to use it now that you aren't going to get pregnant. You are too polite to ask someone their sexual history, because we weren't raised that way. We didn't want to offend by suggesting a condom. (State C ASO Executive Director)

*No Protection.* Three state policymakers and five ASO personnel mentioned that not using protection during a sexual encounter was a risk behavior that older adults exhibit that may be putting them at risk for HIV infection. The fact that a large percent of older adults do not use condoms is certainly supported by literature. However, a few of the respondents also spoke specifically about the lack of condom use within assisted living facilities and nursing homes, which has not been fully explored in research and literature on older adults and sexuality. One ASO Executive Director from State C relayed a story about an incident concerning condoms in a nursing home.

We've actually been to [nursing home] and talked to people there several times. One of the meetings we went to there was this 90 year-old lady and she was very outspoken and was grabbing a lot of condom packets, and she said "These are for my grandkids" and we said "That's okay, take as many as you want." And she said, "But I'm here to tell you that we have sex." And I said "Yes, that's why we are here to talk to you guys." And she said, "No, I'm telling you that people my age have sex." And I said, "Okay, well, take those condom packs and distribute them to whoever." She keeps telling me that "I don't think you understand, these people in this room do have sex." And I said "I understand, that's why we are going to talk to you." So she sees this guy out in the hallway and she went up to him and said "You should have been here! This talk was about HIV!" So a lot of people saw it was very important. That was pretty powerful for those people, too, but I don't think you can get people in that age group to understand that starting over again or finding other partners, that you really have to talk about these things, you can't just assume that they aren't going to get it. (State C ASO Executive Director)

The fact that older adults have a very low level of testing, and therefore do not know their HIV status was only mentioned by one state policymaker as being a behavior that puts older adults at risk for HIV infection. This was not listed by any ASO personnel as being a high-risk behavior, despite the vast amount of literature

and research that shows it is a dangerous trend among older adults.

Additionally, one state policymaker and two ASO personnel mentioned that being a man who has sex with a man (MSM) was a high-risk behavior that puts older adults at risk for HIV infection. This is both surprising and a step in the right direction. It is surprising that being an MSM was only mentioned as being a high-risk behavior that puts older adults at risk for infection by three respondents, considering how HIV/AIDS risk was defined during the formative years of the epidemic. But it is also reassuring that it was mentioned as an individual behavior rather than as a matter of group membership, dispelling the long-standing myth that a person is at risk for infection if they are gay.

The third question I asked about the high-risk behaviors that older adults may or may not be exhibiting that put them at risk for HIV/AIDS was: **Do you think the introduction of Viagra, Cialis, and Levitra has had an impact on the HIV/AIDS infection rate among older adults?** Based on the numbers of new diagnoses and infections in this particular population after the introduction of Viagra in 1998, I argued in Chapter Two that drugs used to treat erectile dysfunction perhaps had contributed to the increase in the infection rate among older adults. I received a mixed reaction from the respondents, ranging from agreement to humor, and some for whom this was a new idea that they had not considered before. Only one respondent, a state policymaker, said that Viagra, Cialis, and Levitra had no impact on the HIV/AIDS infection rate among older adults.

Six state policymakers stated that they believed that Viagra, Cialis, and

Levitra had an effect on the HIV/AIDS infection rate among older adults, and one state policymaker from State D said that older adults are “probably” having sex, so these drugs could have an effect on the HIV/AIDS infection rate. In comparison, eleven ASO personnel believed that erectile dysfunction drugs have an effect on the HIV/AIDS infection rate among older adults. Among these eleven who stated yes, a few mentioned that it has increased the feeling of sexual freedom, such as an ASO Executive Director from State D:

My opinion on what that drug does probably more than not, it gives people a newfound sexual freedom, and I think that with that comes some care-free behavior. So it certainly could be indicative of increasing HIV rates. (State D ASO Executive Director)

This sexual freedom, though important for older adults who previously lacked sexual desire due to medical circumstances or aging, could have negative consequences. A state policymaker from State D pointed out the negative aspects of the use of erectile dysfunction drugs by older adults.

It is something that needs to be looked at because you do have people who are older now that are being more sexually active...they are probably having sex and spreading diseases in a population that we didn't really see that in before. (State Policymaker State D)

Three ASO personnel specifically stated that these types of drugs are likely increasing the rate of HIV infection among older gay men. Additionally, a state policymaker from State C stated that they (state policymakers) had given a survey to HIV-positive gay men in the state and asked about their use of erectile dysfunction drugs, and that “It [linking HIV to the use of erectile dysfunction drugs] didn't seem to pan out” in their survey. Two ASO personnel were quick to point out that these

types of drugs are probably increasing the HIV infection rate among heterosexual men, specifically because they do not consider their risk. An ASO Executive

Director from State D stated,

I think it definitely increases the risk because I think a lot of older adults who are using it, especially heterosexual men, have, it's just off the radar. They just don't think about HIV. (State D ASO Executive Director)

Additionally, a state policymaker from State A pointed out that older heterosexual men are using the Internet to order Viagra, which could also be contributing to the increase of new infections in this population. This is especially dangerous because ordering these types of drugs on-line means that the older adult is not receiving any type of information on the importance of having safe sex while taking the drug.

And the 45+ population, most of them are now literate on the Internet, you can buy it all on the Internet and it's delivered to your door, you do not have to go to your doctor. You may have a 45-year-old son who has a prescription that hands dad a few pills too. "Dad, you are out there having a good time, you shouldn't deny yourself any fun at this stage in the game...try this." (State Policymaker State A)

A few respondents stated that there was a denial about risk behaviors associated with the use of Viagra, Cialis, and Levitra. According to a state policymaker from State D who answered the question in a rather "tongue in cheek" manner, perhaps highlighting the denial that our culture has about who, in fact, uses this type of drugs,

The *ONLY* people using it are the Bob Doles. It's *ONLY* people who are married in committed relationships...and they are *ONLY* using it because they have to procreate and have kids or something. (State Policymaker State D)

Further, an ASO Executive Director stated that, even if older adults are at risk for

HIV infection due to the use of erectile dysfunction drugs, no one is concerned due to the fact that it is an older adult that is infected because of their age.

And, should we really care about old people that much? So what if you are getting infected when you are 70, you are going to die anyway. They are past their earning potential so the business folks don't care. But you betcha there is an increase. I think you can correlate Viagra/Cialis/Levitra with lots of things. You can correlate it with divorces, you can correlate it with infidelity, because it's working now! And certainly with STDs. You betcha. (State B ASO Executive Director)

Surprisingly, when I asked the interviewees about whether or not they saw these drugs as having an affect on the HIV/AIDS infection rate among older adults, a few of the respondents laughed. An ASO case manager from State B stated that, at the time this topic was brought up at a meeting, the first reaction of those in attendance was "Oh, that's funny." It was unclear why the interviewees found humor in this topic, though it could be because older adults and sexuality is seen as a humorous and silly consideration.

Six interviewees (two policymakers and four ASO personnel) had not given any consideration to the fact that these particular drugs could have an influence on the HIV/AIDS infection rate among older adults. A state AIDS director from State B exclaimed, "Huh, I don't know! This is why we need an Office of Men's Health!" when I asked this question, but conceded that they thought there would be an increase because "there would be more people playing the game." Another respondent, an ASO Director from State A, said that, while they have no firsthand knowledge about the possibility of an increased HIV/AIDS infection rate due to erectile dysfunction drugs, they would put a question about it on their intake and case management forms

because it was a reasonable assumption.

In addition to the questions I asked that were specific to older adults, I also asked general questions about HIV/AIDS. One of these questions was: **Who do you see as being at-risk for HIV infection?** It should be noted that I asked this question before I asked specific questions pertaining to older adults. Three of the interviewees, one state policymaker from State B and two ASO personnel from State B and State D, mentioned that older adults are specifically at-risk for HIV infection. An ASO Executive Director from State D mentioned that there are probably older adults who are infected and do not know it because they are not being tested for HIV, which is supported in the literature.

I think that we are probably going to see a couple of different trends in \*\*\*\*\*. One is definitely the elder population because I think that what we know about HIV is that it can live inside your body for up to ten years without showing any signs or symptoms, and I think that there are folks who are probably infected who will find that out later on. (State D ASO Executive Director)

A state AIDS Director from State B mentioned that older adults comprise a significant proportion of new infections in their state, a trend that had been occurring for several years.

As you look at the older adult population, it is the third highest infection rate in the state. It is kind of the middle. It's up a little bit from 2004, up a little bit more from 2003. These are new infections. (State Policymaker State B)

### *Sexual Scripts*

I asked two questions of the interviewees that were related to sexual scripts, specifically the sexual scripts about older adults to which our society adheres. The first question was listed as follows: **How do you think our culture views older**



**adults and sexuality?** Additionally, I used the following prompts to elicit additional responses: **In a positive or negative light, as something to embrace or fear, as something to talk about or ignore? Do you think there are certain rules or expectations that exist concerning older adults being sexual?** The answers provided by the respondents ranged from denial that older adults are even sexual to the thought of older adults being sexual seen as being humorous, disgusting, or shocking. Only a few referred to how sexual scripts about older adults are changing as sexuality is being discussed more openly.

The most common answer given by five state policymakers and four ASO personnel was that our culture views older adults as not being sexual beings at all. As one state policymaker from State C explained,

That [older adults having sex] doesn't exist. I was at a training once, and somebody stood up and said people past 25 don't have sex. People will always think of younger people when they talk about sex and injection drug use, they really don't think about the older population. (State Policymaker State C)

Several respondents echoed a statement made by a state policymaker from State D stated. According to this state policymaker, “We just pretend it [older adults and sex] doesn’t happen. Our mothers and fathers never had sex.” This is a common belief that seems to permeate our culture, regardless of the age of our parents.

If any thought is given to older adults and sexuality, cultural views, according to the respondents, are generally that of humor or disgust. The humor tends to surround older men, as an ASO Executive Director from State C explained:

They think it is humorous. Object of humor. “Why that old fart, what’s he thinking about?” You don’t talk about it. They don’t talk about sex, and if

they do, it's funny...hahahaha. "Grandpa had a woody." (ASO Executive Director State C)

Additionally, an ASO Director from State A pointed out that some of the jokes commonly used in our culture pertaining to older adults and sexuality focus on shame and disgust at the thought of older people engaging in sexual activities.

There's too many jokes about being disgusted by people who are old and having sex, whatever "old" is. There's a disbelief that older people do have sex. It's like, it doesn't happen, so we probably don't have to worry about it. Or they are being "naughty" if they are having sex. Shame involved. People who are older should be ashamed if they are having sex. And so there is no need for education, there is no need to have chats about it. Seems to be in our culture. (ASO Director State A)

An ASO Executive Director from State D raised an interesting point. The Executive Director said that our cultural view of older adults and sexuality is shock at the thought of older adults having sex, a belief that was also found in other research. But what this respondent pointed out is that, in our culture, it is unfathomable and shocking to think of an older having sex outside of the confines of marriage.

I think people think that nobody has sex if they are old. When they find out they do, they are appalled! Shocked! Because they don't fathom that old people are going to consider "getting it on". I think it comes from traditional values and the religious thought, especially if it is someone who is widowed, or maybe their partner is still with them but is incapacitated, that those folks shouldn't be considering having sex. (ASO Executive Director State D)

This ASO Executive Director is from a particularly rural and conservative state, but this idea that older adults are supposed to only have sex within a marriage is perhaps not an uncommon belief in our culture.

Three state policymakers from State B mentioned that they believed our cultural views of older adults and sexuality has began to shift a bit to where it is more

openly discussed. One state policymaker in particular commented that the discussion of sexuality among older adults has “Probably always been there”, and that the state policymaker remembers older men talking about sex during lunch breaks when they worked at factory when the policymaker was in their teens. As they pointed out, “It’s been there all the time, but now we are more ready to document and discuss it.” (State Policymaker State B) Another state policymaker from State B concurred:

People are retiring earlier, that commercial that shows people retiring, the 60s love child and baby boomers jumping out of airplanes, they aren’t going to sit around in their rocking chairs, they are out there conquering the world. (State Policymaker State B)

The second question I asked that was related to the sexual scripts about older adults to which our society adheres was as follows: **If an older adult walked in off the street, what are three things you would tell them about HIV/AIDS?**

According to the literature mentioned in Chapter Two, the risk for transmission of HIV among older adults has specific age-related elements to it. By asking this question, I was looking for the responses of my interviewees to corroborate with what other research has found on the topic, such as the fact that older adults do not use condoms, do not get tested for HIV, or ask about their partner’s sexual history. Further, I was also looking for specific references to older women, who by virtue of their physiological makeup (i.e., the thinning of the vagina with age) are more susceptible to HIV infection. I was coding for age-specific information in the messages the state policymakers and ASO personnel were passing on to the older adult.

Several of the respondents replied to the question about three things they

would tell an older adult about HIV/AIDS in a similar fashion to an ASO Executive Director from State C: “I’d tell them the same things I tell everybody. There is nothing really different.” Telling older adults about how to protect themselves from contracting HIV through the use of protection during sex was the most mentioned piece of information for both state policymakers (n = 5) and ASO personnel (n = 5). Recommending that they change their high-risk behaviors was the second most mentioned piece of information for state policymakers (n = 3) and ASO personnel (n = 4). Other pieces of information that respondents would provide to older adults are to get tested, that they are at risk, and that partners do not always share information about their own high-risk behaviors. A few of the respondents pointed out that HIV shows no preference, and that “Anyone is at risk regardless of where they live, regardless of their age, and regardless of whether they are gay or straight” (ASO Executive Director State A). As a state AIDS Director from State A explained,

I would explain to all that age shows no barrier, that...that...you know, it doesn’t make a difference if they are 65 or if they are 80. It just takes once, you know. (State Policymaker State A)

Due to the stigma attached to HIV/AIDS in the U.S., talking to people about their own risk could be a complex situation. Perhaps because of the existing sexual scripts about older adults, or the sexual scripts that older adults adhere to, this conversation can be even more complicated. An ASO Executive Director from State D explained this situation:

I think the first thing is that I would tell them what I consider the risk, which is anybody who has unprotected sex and puts themselves at risk not only for HIV but other STDs, Hep C, so there is a lot to be at risk about. I think that would probably be something that is probably difficult for older adults to hear,

and I think that having the conversation and letting them start to normalize them would support them. (ASO Executive Director State D)

During the coding process, I discovered that state policymakers mentioned eight times that they would provide age-specific information. These codes included the fact that age is no barrier (n = 2), that older adults can contract HIV and they are not immune (n = 4), and older adults are at risk and shouldn't be overlooked (n = 2). This last code was emphasized several times by a state AIDS Director from State C:

Most importantly, not to overlook this in the older population, people their age, because...I think people are surprised when we say that our average age of diagnosis is right at 40. So that is the piece right there, that's important to know. Don't overlook HIV. (State AIDS Director State C)

ASO personnel mentioned age-specific information six times. These included that older adults are at risk (n = 2), that HIV had no boundaries (n = 2), and HIV infects people of all ages (n = 1). Additionally, an ASO Executive Director from State B mentioned that they would tell older adults that "It's increasing, HIV itself is increasing among their age group, and they can protect themselves."

In addition to asking the interviewees about the three pieces of information about HIV/AIDS they would provide to older adults, I also asked if the information would change if the older adult were a gay man (one of the first and hardest hit groups of the epidemic) or a woman (one of the fastest growing populations of new infections). For the prompt about gay men, all of the responses from state policymakers were that they would provide the same information to the older adults if they were a gay man. When asked the same question, most of the ASO personnel also said they would provide the same information that they would provide anyone.

However, five of the respondents said they would provide more specific information that is more applicable to gay men. For example, two of the ASO personnel mentioned that they would emphasize the risk associated with anal sex more with older adults who were gay men. As an ASO Executive Director from State D explained,

Of course with talking with them about their sexual practices, it might be a little different for a heterosexual person versus someone who is gay. You would want to talk more specifically about anal sex. I would actually talk to both about oral sex, but I might be a little more explicative with someone who is a gay man because we know oral sex is more of their culture, whereas if someone is over 45 from what I understand a lot of folks don't consider that to be a social more. (State D ASO Executive Director)

Three of the ASO personnel respondents stated that they would change the information they provided to older adults if the older adult were a gay man because gay men face a higher risk for contracting HIV than other older adults. An ASO Executive Director from State B addressed the fact that some older adult men do not identify themselves as gay because they are married to women, yet continue to have sex with men on the side. This practice has forced this ASO Executive Director to change their message about HIV/AIDS protection, as is evidenced by the following statement.

Yes, especially if he is a gay man. Numbers-wise that's still...interestingly enough, less than half of the population we serve identify themselves as gay or bisexual. There are lots of married men who are having sex at the park, or at the bookstore, with other men. This fascinates me...they don't consider themselves gay because they are married with 2.1 children. So now the messages have to be geared towards MSM [men who have sex with men]. I'm like, what the hell? That means you are gay. No, not if you are married and go to the Baptist church and have 2.1 children. And that has been an issue for us. (State B ASO Executive Director)

I asked the interviewees if their message would change if the older adult were a woman. Only one state policymaker, a state AIDS Director from State C, said that the message would change a bit if this were the case. According to this respondent, women should not trust their partners to be completely honest about their sexual history.

Specifically for a woman I would say, only because I'd hope that gay men think this way already, but don't expect that your partner has told you everything. And be completely honest. Since we know that a lot of the positives come from when a partner hasn't been honest with the other. (State AIDS Director State C)

When I posed this question to ASO personnel, six of the respondents said that they would change their message if the older adult were a woman. Specifically, two of the respondents commented that older women are more at risk for contracting HIV than younger women because of the physicality associated with transmission through sex, such as the thinning of the vaginal walls. An ASO Executive Director from State C addressed this issue:

I would say that, because the vaginal wall could be drying or thinning, that it could be easier...maybe you didn't get infected in the last 15 years with that positive partner you are with, but maybe you will because of some of those things, your risk might be higher because of that. We recommend that, if they are with a new partner that they both go and get tested before they have unprotected sex even though they are 65. I would also tell people that they don't have to have sex...you can be a born-again virgin at 65, you don't have to have sex. Talk. Do other things until you are sure that the person isn't infected or going out on you. (ASO Executive Director State C)

Four of the ASO personnel respondents stated that they would change their message about HIV/AIDS for older adult women because partners are not always truthful about their sexual history or they cheat. An ASO Executive Director from

State C explained that they would tell older women not to trust everything their partners tell them about their sexual history.

I think I would tell women “Don’t always trust the man.” Because a lot of women still think that their husband or their boyfriend would never...and call me cynical, but I think any man in the right position will. Don’t be stupid! (ASO Executive Director State C)

An ASO Executive Director from State D stated that they would take this conversation with older women one step further and suggest to them that they talk to their partners about cheating. This respondent explained that it was actually a matter of life or death for older women.

For women, I would actually have the same three conversations but they would be a little bit different. It would still be the same three issues, but I would concentrate on a little bit more would be about getting tested and knowing your status, and about effective communication with her partner. A line that I use to tell women in talking with their partner to let them know it is one thing if you go out and cheat on me, but it’s another thing if you risk my life, so if you are going to cheat, use a condom. It would be more about effective communication. Because historically we know when heterosexual females become positive who are in monogamous relationships it’s usually because their partner’s been outside of the marriage. (ASO Executive Director State D)

### *Prevention Education*

In order to ascertain whether or not older adults were viewed as being at risk for HIV/AIDS infection, I asked all of the interviewees about the types of prevention education that was made available to older adults. Specifically, I asked: **What types of health promotion, prevention services, or education for HIV/AIDS do you provide to the older adult population?** As a prompt, I followed this question with: **Do you offer any education or information specifically geared towards older adults?** All of the state policymakers responded that they provide the same



prevention education to older adults as they do to all other populations. Twelve of the ASO personnel also stated that they provide the same types of health promotion and prevention education to older adults as they do to anyone else.

However, three of the ASO personnel did offer age-specific HIV/AIDS information and prevention education for older adults. An ASO Executive Director and Education Specialist from State D both mentioned the fact that they were just beginning to offer age-specific HIV/AIDS information to older adults, and they were targeting the 55+ age group. This was due to a specific request they received from the community to provide prevention education to seniors who lived in senior housing. Another ASO Executive Director and a Volunteer Coordinator from State A mentioned that they display information at health fairs that are specifically for seniors in order to reach that particular population.

Out of the thirty-one interviews I conducted, only one—an ASO Director from State A—had actual HIV/AIDS educational materials that were specifically for older adults. This ASO Director noticed that some of the population they were seeing coming in for HIV tests and HIV information were in the older adult age cohort. Because the ASO Director was not able to find any educational materials that were specifically geared towards older adults, they made their own flyers and brochures. When I asked about these materials, the ASO Director replied:

I think it's in my health fair box. I have something called “Older Americans and HIV.” I have it in a box I take to [health] fairs. I noticed that, if I'm sitting at the table, they [older adults] do not pick them up. If I'm not sitting there, if I'm talking to the person next to me, they definitely take the pamphlets up if nobody is watching. They rarely stop and talk. (ASO Director State A)

Three of the ASO personnel explained that there was simply not enough money to provide focused interventions to older adults. As one ASO Executive Director from State C exclaimed, “Show me the money!!!!” It is not necessarily that the respondents did not want to provide focused interventions to this population; it was the fact that they lacked the funds to do so that was impeding prevention education for older adults, as an ASO Executive Director from State D explained: “More than anything else it is based on our funding, we would love to have focused interventions for all groups, but we are just not able.”

Even though this particular population is one of the fastest rising populations of new HIV infections, they are not considered a target group by most of the ASOs. An Executive Director at an ASO in State C mentioned that the pictures and information they put on their pamphlets are young adults, and generally MSMs (men who have sex with men) and IDUs (intra-venous drug users). When I asked why older adults are not being targeted, an ASO Volunteer Coordinator from State A answered bluntly in a sarcastic tone that “Older adults, older gay people don't matter. They have no value. They are invisible. Because of that, what it says is so what if you die when you are 40?” Further, a state AIDS Director from State D stated that, even if the ASOs and the state provided prevention education to older adults, the message would not necessarily be received unless it was a member of the older adult community who was spreading that message.

There needs to be people in older populations that are helping to carry that message. You need a little old lady to go in and talk to the Red Hat club...that's the only people that are going to get in there to talk to them. It's not going to be a young woman, a young man, it's got to be a little old lady

that looks like them. (State AIDS Director State D)

As I mentioned earlier in this chapter, I asked several general questions about HIV/AIDS, some of which will be used in future research. One of the questions was “Who do you see as being at-risk for HIV infection?” which was answered earlier. I also asked the question: **What has the reaction of physicians in your area been to the HIV/AIDS crisis?** I did not anticipate that this question would illicit responses that had any type of age-specific focus, and several of the responses I received did not. However, a few of the answers did relate to older adults, and most certainly reflected the findings from other research and literature on the fact that physicians do not talk to their older adult patients about safe sex or sexuality.

For example, an ASO Executive Director from State C stated that doctors in their area were not trained to talk to older adults about safe sex. They said that “They [doctors] aren’t comfortable doing that because they haven’t been trained and they don’t know what to say.” This sentiment was also communicated by another ASO Executive Director in State C, who pointed out that “Grandpa and Grandma aren’t having sex. I can’t imagine doctors are asking older adults about their sexual habits.” As was pointed out in Chapter Two, research revealed that doctors do not talk to older adults about their sexual habits, and therefore are not in a position to provide HIV/AIDS prevention education to older adults. A state HIV/AIDS Surveillance Director from State B relayed their own personal experience with this subject by stating “I’m 54, and I don’t think any physician I’ve ever visited has asked me about my sexual history or status or those kinds of things.”

ASO personnel from two states provided examples of how physicians act as barriers against HIV/AIDS prevention education and health promotion. An ASO Executive Director from State B told a story of having an older female client who requested an HIV test due to physical symptoms she was exhibiting, but her doctor told her she did not need a test.

Sure and that's still out there [physician ignorance], and we still have rural providers...we had an older client who kept going because she had real funky stuff, and she asked the doctor if she needed an AIDS test, and he said "No, good girls don't get AIDS". A month later she is in the hospital half dead because he didn't think she needed an AIDS test. (ASO Executive Director State B)

This was not the only example provided by the respondents of a physician acting as a gatekeeper (in their opinions) to HIV/AIDS prevention education. An ASO Volunteer Coordinator from State A gave the example of their mother being denied an HIV test by her doctor, even though she admitted to him that she was exhibiting behaviors that put her at risk for HIV infection.

I think it's generational... they don't talk about it for one thing. But living in small towns, everybody knows everybody else's business so they talk about it, but it's not openly talking about it. My mother went to the doctor and she was in her 60s at the time and having unprotected sex, and so I told her to say to her doctor that she would like an HIV test, because my son has talked to me about this and I've been participating in high-risk behaviors. He wouldn't do it. He said, "You are *SO* not a risk for me to do it." In rural areas, doctors are such authority figures, especially with the older generations who do not ignore the doctor. If he tells you something, you do it. (ASO Volunteer Coordinator State A)

## **Additional Methodology**

### *Organizational Ethnography*

In addition to performing interviews, I also wanted to better understand the

day-to-day inner-workings of an ASO. In order to do this, I offered my time and services to the ASO as a volunteer. After each of my days of volunteering, I wrote down notes and observations I made during my time at the ASO. Admittedly, much of the data I collected during this time will be used in future work on ASOs as struggling organizations. However, for purposes of this dissertation, I coded my notes with a specific focus on anything having to do with aging or older adults. As a reminder, for purposes of confidentiality, I renamed the ASO “Positive Action.”

There were only two occasions in which I noted a specific focus on older adults. First, the Executive Director of Positive Action informed me during our first meeting that the ASO has had a significant amount of clients who are in the over-50 age category. They pointed out that, over the past few years, the percentage of clients who were in this age cohort ranged from 19-25%, which even surprised the Executive Director once they realized how many of their clients were considered “older adults”.

A second occasion in which I noticed a specific focus on older adults occurred when I volunteered to help run an education table for Positive Action at a local establishment. The other person I volunteered with was a very prominent member of the community and held a high-profile job. Three different older men whom the volunteer personally knew walked by the education table, and the volunteer asked them “Do you have someone in your household who could use condoms?” All three of the older men looked at us sheepishly and shook their heads “no” before chatting with the volunteer. The volunteer later confided in me that each of the men had a teenage child, and that is who the volunteer was referring to when they asked if

someone in their household could use a condom. However, two out of the three men were single, and all were in their 50s. The volunteer did not ask them if they needed condoms, but instead assumed the only reason they would need condoms was for their children to use. The thought did not cross the volunteer's mind that perhaps the men themselves could use the condoms or needed to practice safe sex while back on the dating scene.

#### *State HIV/AIDS Consortia Meetings*

Another form of data collection for this dissertation was through attendance at HIV/AIDS Consortia meetings. As a reminder, each state that receives Ryan White CARE Act monies (and all fifty states do) is required to hold state Consortia meetings. I attended state HIV/AIDS Consortia meetings in each of the four states during the summer of 2006. I took detailed notes on the topics of discussion, the interaction between different Consortia members, and various observations. Again, for purposes of this dissertation, I was listening for specific information related to aging or older adults.

After attending the first of the four Consortia meetings, it became apparent to me that older adults were going to be excluded from any discussion about groups at risk for HIV/AIDS infection. The meetings consisted of discussing funding issues, and which groups for whom the CDC and federal government decided to fund health interventions (mainly gay men, young adults, and minorities). Even though the statistics about infection rates and demographics distributed during the meetings clearly showed that older adults were increasingly becoming a group at risk for new

infections, it was clear that the states and the Consortia were bound by the guidelines set by the CDC and federal government. Because funding is ultimately decided and monitored by these federal agencies, the fact that the HIV/AIDS rate among older adults is increasing in these four states is not enough to change the current funding situation. Prevention education and health promotion focused on older adults may not increase in the foreseeable future.

#### *State HIV/AIDS Comprehensive Plans*

In addition to the requirement to have a state HIV/AIDS Consortia, each state is required to assemble a state HIV/AIDS comprehensive plan, which is a conglomeration of information about HIV/AIDS in the particular state, including demographic information about those infected, predictions of infection rates and groups at risk, funding issues, and future areas of concern. I conducted a content analysis of the state HIV/AIDS plans of the four Midwestern states to identify age-related dimensions of the plans, and also conducted a content analysis of four other states with higher rates of older adults among their population and higher incidences of HIV infection and AIDS cases (California, Texas, Florida and New York) as a comparison. I was specifically coding for any mention of older adults.

The only age-specific information about older adults in the four Midwestern state HIV/AIDS comprehensive plans were the reported percentages of older adults who were infected with HIV or diagnosed with AIDS. The numbers and percentages from each state reveal that the older adult population makes up a significant proportion of the HIV/AIDS population in each state. The four tables below show

what percentage of the HIV and/or AIDS population that older adults comprise in each of the four Midwestern states in this dissertation. Because each state started tracking their HIV diagnoses at different times and also track their age groups differently, the tables are not comparable to each other. State A provided percentages who were older adults (45-49 years, and 50+ years) among those newly diagnosed with HIV and AIDS from 1996 to 2003.

**Table 5.4: State A HIV and AIDS Diagnoses, Cumulative From 1996 through 2003**

<b>Diagnoses</b>	<b>HIV Cumulative through 2003</b>	<b>AIDS Cumulative through 2003</b>
<b>45-49 years</b>	16% of HIV population	22% of AIDS population
<b>50+ years</b>	5% of HIV population	9% of AIDS population

Source: State A Health and Human Services System HIV/AIDS Surveillance Report 2003

State B provided percentages who were older adults (40-49 years, and 50+ years) among those newly diagnosed with HIV and AIDS from 1987 through 2003, as well as the combined percent of those infected with either HIV or AIDS from 1987 through 2003.

**Table 5.5: State B HIV and AIDS Diagnoses, Cumulative From 1987 through 2003**

<b>Diagnoses</b>	<b>HIV Cumulative through 2003</b>	<b>AIDS Cumulative through 2003</b>	<b>HIV/AIDS Cumulative through 2003</b>
<b>40-49 years</b>	15.2% of HIV population	22.3% of HIV population	20% of HIV population
<b>50+ years</b>	4.6% of HIV population	9% of HIV population	7.5% of HIV population

Source: State B Epidemiologic Profiles 2004

State C provided percentages of the newly diagnosed with HIV and AIDS who were older adults (45+ years) in 2002, as well as newly diagnosed AIDS cases from 1998 through 2002.



**Table 5.6: State C HIV and AIDS Cases in Adults 45+, 2002 and Cumulative From 1998 through 2002**

	<b>HIV 2002</b>	<b>AIDS 2002</b>	<b>AIDS Cumulative through 2002</b>
<b>45+ years</b>	17% of HIV population	25% of AIDS population	21% of AIDS population

Source: State C Comprehensive HIV Plan 2004-2006

State D State B provided percentages of the newly diagnosed with HIV and AIDS who were older adults (45+ years) in 2003, as well as newly diagnosed AIDS cases from 1999 through 2003.

**Table 5.7: State D HIV and AIDS Cases in Adults 45+, 2003 and Cumulative From 1999 through 2003**

	<b>HIV 2003</b>	<b>AIDS 2003</b>	<b>AIDS Cumulative through 2003</b>
<b>45+ years</b>	20.4% of HIV population	19.8% of AIDS population	16.2% of AIDS population

Source: State D Integrated Epidemiologic Profile for HIV/AIDS Prevention and Care Planning 2004

These are new diagnoses and not examples of older adults aging into older adulthood with HIV or AIDS. Further, it should increasingly appear how difficult it is to truly understand the landscape of HIV/AIDS in the U.S. due to the different means of tracking each state employs. However, the fact remains that older adults are a significant part of the HIV/AIDS population in each of these four Midwestern states. Despite this fact, not one of the Midwestern HIV/AIDS comprehensive plans addressed this population.

I also examined the HIV/AIDS comprehensive plans of four comparison states: New York, Florida, Texas, and California. The sheer volume of HIV/AIDS infections in these four comparison states is significantly larger than the numbers in the four Midwestern states. However, the percentage of the total U.S. HIV/AIDS population who are older adults mimics that of the Midwestern states. The difference

that I'm highlighting between the Midwestern HIV/AIDS comprehensive plans and the four comparison state's HIV/AIDS comprehensive plans was that each of the comparison states addressed the growing issue of older adults' HIV risk.

For example, New York's HIV/AIDS comprehensive plan contained a section specifically about older adults over the age of 50. Along with providing percentages and numbers of persons living with HIV/AIDS in the 50+ age category, the comprehensive plan also stated that older women are increasing among the numbers of newly infected individuals, and that the data refutes the misperception that HIV-infected older adults are predominantly gay White males who have aged into this category. Further, the HIV/AIDS comprehensive plan clearly states that there is a denial of risk among seniors, a lack of education about HIV for seniors, and ageism that is manifested by seniors being ignored by clinicians. As the plan succinctly states,

Service models should include culturally sensitive HIV education targeted to persons in the 50 and over age range and better integration of HIV prevention, care and supportive services with other programs serving seniors (105).

The other three HIV/AIDS state comprehensive plans from Florida, Texas, and California all address the fact that older age groups (either 45+ or 50+, depending on how the state tracks their numbers) showed the highest rates of increase in new infections and diagnoses. In Texas, new infections in each age cohort over 45 years increased at least 40% between the years 2000 and 2004. Florida and California's older adult populations are most certainly at risk for contracting HIV; the older adult population made up between one-third to one-half of the cumulative (through 2002

and 2005 respectively) AIDS cases and HIV cases in each state. In fact, older adults are becoming newly infected with HIV at such an alarming rate in California that they were deemed a “priority population” for the first time in 2005. As the California state HIV/AIDS comprehensive plan stated, “The diseases of aging interact with HIV disease to make care more complicated and costly” (55).

The four comparison states are beginning to realize the physical and economic ramifications of HIV/AIDS in the older adult population. Unfortunately, the four Midwestern states I focused on in this dissertation are not doing the same. As the numbers of newly infected older adults and those who have aged into older adulthood already infected continues to increase, the importance of including older adults in state HIV/AIDS comprehensive plans will become more apparent in the Midwest. It may be only a matter of time before the issues of long-term care for infected older adults that are currently plaguing the four comparison states make their way to the Midwest.

It is evident from the data I collected that there are many different issues concerning older adults and their risk for HIV infection at play on multiple levels. In the next chapter I will analyze the data and findings presented in this chapter. Further, I will examine the extent to which sexual scripts and risk may have had an effect on how state policymakers and ASO personnel addressed the issue of older adults and HIV/AIDS.

## **Chapter 6: Analysis and Discussion**

My purpose in this dissertation project was to examine the effect of sexual script theory and a sociology of risk on the social construction of a public health crisis. I accomplished this task through the process of discovering if older adults were omitted from HIV/AIDS prevention and outreach at the state and community-level and, if so, for what reason(s). I also sought to determine what factors influenced the type and amount of HIV/AIDS prevention education being provided to older adults. Several questions guided my research: If older adults were, in fact, being ignored in state and local-level HIV/AIDS prevention education was it because policymakers and health educators did not think older adults exhibit enough risk behaviors for HIV? Do sexual scripts about older adults influence the amount and type of HIV/AIDS education and prevention provided by state policymakers and ASO personnel? Finally, could social factors be influencing the amount and type of HIV/AIDS education and prevention services targeted towards older adults?

In this chapter, I answer the questions posed above by analyzing the data I collected via qualitative interviews with state HIV/AIDS policymakers and ASO Executive Directors or personnel, data collected during the organizational ethnography I conducted at an ASO, the notes I took at my attendance at the four state HIV/AIDS Consortia meetings, and the age-specific data I coded in the four Midwestern states' HIV/AIDS plans, as well as those of four comparison states. The themes that emerged from this dissertation reinforce previous research on sexual scripts pertaining to older adults and risk factors, but also suggest new insights and

interpretations into possible reasons why older adults are omitted from HIV/AIDS prevention education in the Midwest. I have separated this chapter into three sections.

### **Older Adults and HIV/AIDS Risk**

In the case of HIV/AIDS, deciphering risk level is based on an assessment of specific behaviors exhibited and whether or not they have the potential to result in infection. Because risk estimates are socially constructed, we must keep in mind that other social factors—particularly stereotypes and sexual scripts—might be influencing who is seen as being at risk for HIV/AIDS infection. This was the case when I asked state policymakers and ASO personnel about the risk of older adults contracting HIV/AIDS.

In order to ascertain why older adults are left out of HIV/AIDS prevention education in the Midwest, I hypothesized different explanations. Are older adults excluded from state and local-level HIV/AIDS prevention education efforts because policymakers and health educators do not think older adults exhibit enough risk behaviors for HIV? Responses from state policymakers and ASO personnel indicate that the respondents did, in fact, believe that older adults exhibited behaviors that put them at risk for HIV infection. The respondents exhibited a high level of knowledge concerning possible transmission routes for HIV infection and behaviors that are considered high risk for infection among older adults.

It should be noted that ASO personnel provided more examples of risk behaviors exhibited by older adults, and the examples provided were more specific.

For example, whereas a small number of state policymakers acknowledged that older adults returning to the dating scene could lead to behaviors that put them at risk for HIV infection (i.e., sexual scripts of older adults: not using condoms, not worrying about pregnancy, not discussing sexual history, etc.), a larger number of ASO personnel saw this as a possible risk behavior that could lead to infection. The fact that ASO personnel are essentially at the “ground level” within their communities while state policymakers are basing their opinions on raw data could be the reason why more ASO personnel are better able to recognize the risk behaviors exhibited by some older adults. However, this does not bode well for these four states, as the state policymakers participate in the distribution of federal funds (including those used for prevention education) to communities within their states. If the state policymakers are not made fully aware of the fact that older adults are exhibiting risk behaviors that could result in contracting HIV, this could be a contributing factor as to why older adults are left out of HIV/AIDS prevention education.

While the respondents were well aware that older adults within their communities exhibit certain behaviors that potentially could result in contracting HIV, overall this did not translate to recognizing this population as a whole as being at risk. The responses of the state policymakers and ASO personnel reinforce findings that older adults are not seen as being at risk for HIV/AIDS infection (Falvo & Norman 2004; Genke 2000). This disconnect was puzzling given the fact that the respondents readily agreed that older adults in their communities were exhibiting behaviors that were considered high-risk for infection. But somehow being cognizant

of the high-risk behaviors exhibited by older adults did not mean that they viewed the whole older adult population as being at risk. I can only conjecture that the older adults the respondents thought were exhibiting high-risk behaviors were considered outliers in the older adult population of the respondents' particular state, and that the rest of this population was not at risk. However, even if this is a true statement, the typical protocol of public health is to target a population who exhibit dangerous or risky behaviors and then provide interventions or behavioral modifications (Gazmararian et al. 2005; Morgan & Tyler 1971). The fact that these older adults who are at risk for infection are not receiving any interventions or prevention education is still perplexing.

However, this disconnect was not necessarily unexpected. As mentioned earlier, much of the literature and research in this area has shown that, despite the long-standing call for sex education interventions by researchers (White and Catania 1982, for example), older adults have been, and continue to be, left out of HIV/AIDS prevention education policy, both nationally and at the state level (Falvo & Norman 2004; Stombeck & Levy 1998). My findings were consistent with this research, as only three of the thirty-one interviewees mentioned that older adults are at risk for HIV infection, and only three interviewees (all ASO personnel) offered age-specific HIV/AIDS information and prevention education for older adults. This information included a very short presentation given by two of the interviewees and a pamphlet made by one of the respondents. These three respondents, all ASO personnel, saw this need in their respective communities and made the decision to provide

information and prevention education on their own.

The behaviors that put older adults at risk for HIV/AIDS infection—having sex, not getting tested, adhering to sexual scripts that do not include frank and open discussion about safe sex and protection, etc.—are essentially the same behaviors that younger adults exhibit. Several state policymakers and ASO personnel pointed out these behaviors but later associated HIV risk with specific populations, such as gay men, minorities, and younger adults, but rarely with older adults. If the behaviors that older adults are exhibiting are the same as those exhibited by younger adults, gay men, and minorities, why is it that state policymakers and ASO personnel do not associate HIV risk with older adults?

I expected to answer this question by explaining that state policymakers and ASO personnel were adhering to existing sexual scripts about older adults. However, the fact that the interviewees listed specific behaviors that older adults exhibited that could put them at risk for HIV infection caused me to consider other possible explanations. The state policymakers and ASO personnel were not necessarily supporting sexual scripts about older adults which indicate that older adults were asexual or not at risk for HIV. In fact, both groups were open to the possibility that older adults did exhibit risk behaviors that could result in new infections. In an effort to explain why older adults were excluded from HIV/AIDS prevention education, I did find that sexual scripts were, in fact, a guiding force, though not in the way I had anticipated.



## **Sexual Scripts**

### *State Policymakers and ASO Personnel*

Our culture's stereotyping and sexual scripts about older adults as asexual and therefore not exhibiting risk behaviors is anything but rare, as is evident from the literature I analyzed in Chapter Two. In this study, I found that state policymakers and ASO personnel are aware that society holds stereotypes and sexual scripts about older adults. A number recognized that our culture views older adults as not being sexual beings, or are subjects of humor or disgust. As a whole, most interviewees answered questions in such a way that indicated they were critical of society's views of older adults and sexuality.

The respondents were also aware that older adults themselves adhere to society's sexual scripts which tell them that they are not at risk for infection for various reasons (past childbearing stage, do not use condoms because they grew up in an era when condom use was not common, do not discuss sexual history, etc.). When I asked what HIV/AIDS prevention education they would provide to older adults who walked into their ASO or state office, several of the respondents stated that they would tell them the same things they would tell anyone else. This recognition that older adults are just as vulnerable as younger adults to HIV infection due to specific exhibited behaviors dispels common myths about older adults and sexuality.

As a group, state HIV/AIDS policymakers and ASO personnel were also cognizant of the fact that the disease itself is laden with stereotypes and misconceptions. For example, only three respondents mentioned that being an MSM

was a high-risk behavior that puts older adults at risk for infection. This is most certainly a departure from society's view of HIV/AIDS as being a risk to only gay men.

This is not to say that cultural sexual scripts about older adults did not have any influence over the respondents' views. Some of the state policymakers and ASO personnel who were critical of society's views of older and sexuality also exhibited signs of adhering to society's sexual scripts of older adults. For example, the ASO volunteer who helped to hand out condoms while sitting at an HIV/AIDS educational table did not consider that older single men need condoms to practice safe sex while back on the dating scene. The assumption may have been that these older men were not sexual, or knew how to practice safe sex and therefore did not need any condoms (which the literature [Altschuler, Katz & Tynan 2004, for example] says is highly unlikely). Either way, they were overlooked as candidates for HIV/AIDS prevention education.

Another example of some state policymakers and ASO personnel adhering to sexual scripts about older adults occurred when I asked whether state policymakers and ASO personnel believed that the use of Viagra, Cialis, and Levitra (erectile dysfunction drugs) and hormone replacement therapy played any part in the increasing numbers of new infections in older adults. Based on an analysis of new HIV infection numbers during the year Viagra was introduced and the years following, I began to explore the possibility that these types of drugs, in combination with a lack of HIV/AIDS prevention education being provided by the prescribing

physicians, were increasing the numbers of newly infected older adults. There has been a bit of research on the topic that reinforces my hypothesis (San Francisco Department of Public Health 2005; Klausner 2002), but this appears to be a gap that could be an important area to explore.

I received a mixed reaction from state policymakers and ASO personnel, ranging from agreement to humor to not being a previous consideration. A few of the respondents pointed out that heterosexual men were probably most at risk when using these types of drugs, because they might not be receiving prevention education when being prescribed the drugs (though I wonder if older gay men would receive prevention education when being prescribed these drugs). Admittedly, this was the response I was hoping to receive. Because the literature clearly lays out the fact that heterosexual sex was the primary mode of transmission for new infections (THJKFF 2007g; ACRIA 2006; Emler, Tangenberg & Siverson 2002), I believe that there is a real possibility that erectile dysfunction drugs may be contributing to this phenomenon.

What surprised me was the fact that a few of the interviewees—some of whom were ones who were critical of our culture's response to older adults having sex—responded to the question by laughing. It was unclear to me whether the respondents found humor in the fact that older adults are using these types of drugs, or the thought of older adults having sex. Either way, it indicated to me that perhaps some cultural sexual scripts about older adults were still having some affect on state policymakers and ASO personnel. Further, the fact that several interviewees had not

given any consideration to the fact that these particular drugs could have an influence on the HIV/AIDS infection rate among older adults perhaps indicates that older adults may still be invisible when considering who is at risk for HIV infection.

A few of the respondents who were surprised by the thought that these drugs could be connected to the increase in numbers and percentage of newly infected older adults did say that they would begin to explore this possibility in their ASO. One respondent even mentioned that they would begin to incorporate this possibility into their HIV/AIDS curriculum that they provided at health fairs and presentations. I took this as a sign that, despite the opportunity to adhere to cultural sexual scripts about older adults, there are state policymakers and ASO personnel who are rising above the sexual scripts and stereotypes and are willing to consider any possibility of risk in order to better educate individuals about HIV/AIDS.

### *Physician Influence*

Something I had not considered as having as great an impact as it did on the provision of HIV/AIDS prevention education was physician influence. I had anticipated that I would hear references to physicians being reluctant to discuss issues of sexuality with older adults, which would reinforce previous research on the topic (Langley 2006; Hayes Taylor 2004; Coon, Lipman & Ory 2003; Orsulic-Jeras, Sepher & Britton 2003). The data I collected did reinforce these findings, but also added another element that I had not come across in the literature and research on the topic.

What I found was that some respondents viewed local physicians as

gatekeepers for patients' receiving HIV prevention education. Further, some respondents believed that physicians (especially in smaller towns and rural areas) could also serve as barriers against testing, even if the older adult requests an HIV test or prevention education. Something I heard repeatedly during the interviews was that physicians in rural areas and small towns had a large amount of influence over older adults, who often took the physicians' word as authority. If older adults were told by their physicians that they were not at risk and therefore did not need to be tested or receive HIV/AIDS prevention education, there was nothing the ASO personnel could do to provide prevention education to this population. Further, several interviewees voiced frustration with having to educate physicians and medical personnel about HIV/AIDS at the same time as trying to work in partnership with them to help provide HIV/AIDS prevention education to the communities.

Based on this information, I conclude that there could potentially be a pattern in which physicians in these four Midwestern states hold stereotypes and adhere to sexual scripts about older adults which indicate that they are not at risk for HIV infection. Because of this, older adults are less likely to receive HIV/AIDS prevention education from medical personnel. This could be a dangerous trend, as older adults are probably more likely to speak to their doctor about such intimate information than a stranger at an ASO. However, because I did not interview physicians or older adults for this project, this is a hypothesis that should be explored further in future research.

## **Social Factors**

Sexual scripts certainly played a significant role in whether older adults in the Midwest are being provided with HIV/AIDS prevention education and health promotions, though not in the way I had originally anticipated. In respect to one of my research questions I would argue that the sexual scripts about older adults do have an influence over whether older adults are being provided HIV/AIDS prevention education. However, it is not adherence to sexual scripts by state policymakers and ASO personnel that is having the greatest influence on whether or not older adults are being provided with HIV/AIDS prevention education. Rather, it is federal government agencies who distribute funding to communities within the four Midwestern states who may be allowing stereotypes and misconceptions about older adults, as well as about HIV/AIDS itself, to guide their decision-making process.

In order to understand if other factors were playing an important part in why older adults are not receiving HIV/AIDS prevention education in the Midwest, I began to examine the data and look for specific social trends that could be important. For starters, it was obvious from attendance at State Consortia meetings that the Consortiums, who ultimately set state HIV/AIDS budgets and distribute funds given to the state, are bound by guidelines set by the CDC and federal government. The CDC and federal government ultimately decide which groups are considered (or socially constructed) to be “risk groups” based on past trends (gay men and IDUs, for example) and current numbers (minorities), and few other groups within the general population are included. Because funding streams follow risk groups, little money is

left over to help fund HIV/AIDS prevention education for other sub-groups of the population.

I would argue that it is the enduring stigma that is attached to a disease thought to be a product of the bearer's behavior that resulted in certain sub-groups of the general population being targeted for prevention education and interventions while other groups are virtually ignored. Despite the fact that the numbers and rates of infected older adults are increasing, funding is attached to stigmatized groups who are thought to be in need of HIV/AIDS prevention education and health promotion merely by group association. This has been typical of how federal funding for HIV/AIDS has been distributed since the early years of the U.S. epidemic. Groups that were either highly affected early on (gay men and intravenous drug users) or are increasing in numbers (minorities and youth) receive a huge proportion of funding for prevention education, and the targeted funding must be used solely for that particular group. Perhaps because it is difficult to picture someone's grandmother as being at risk for HIV infection, federal money is not being provided to address this population. Therefore, the four Midwestern states and ASO personnel in this dissertation project are unable to afford to provide targeted prevention education to older adults, even if they wanted to. As some of the interviewees pointed out, prevention education is based on their funding, and they are simply unable to provide this service to older adults.

Another social factor that may be affecting the level of HIV/AIDS prevention education being provided to older adults in the Midwest is the conservative views of

local and state governments. During the performance of a content analysis of state HIV/AIDS comprehensive plans, I found that the four Midwestern state plans did not mention older adults at all, while the four comparison state plans (New York, Florida, Texas, and California) all provide detailed information and in-depth discussion about how older adults should be seen as a priority population. There were open and frank explanations of older adults' risk behaviors within these four comparison state plans, all of which may have been a bit too controversial or offensive in a more conservative state. These comparison state plans also highlight the fact that diseases associated with aging interact with HIV infection, which can make care costly and complicated. Additionally, the comparison state plans recommend that this group be targeted for prevention education due to the increasing numbers and rates.

Admittedly, the four comparison states all have much larger amounts of older adults who are infected with the virus. But the Midwestern states have similar percentages (and some are higher) of their HIV/AIDS population who are older adults as the U.S. does as a whole. This could indicate that the Midwest will face similar problems as the four comparison states in trying to prepare for the long-term costs of caring for infected older adults. In other words, the current crisis in the four comparison states could be an indication of what is to come in the Midwest if older adults continue to become newly infected or age into older adulthood with HIV/AIDS.

The fact that the four Midwestern states do not focus on older adults appears to have, at least in part, roots in conservative political and social views. The state



policymakers and ASO personnel made mention of the conservative views of their respective state, communities, and citizens several times throughout their interviews. Further, when asked about how society views older adults and sexuality, the interviewees responded that it simply does not exist, is an object of humor, or is disgusting. Based on the conservative views that exist within the four Midwestern states, one could assume that these would be common responses of residents. On the other hand, the four comparison states may have less conservative views, and therefore are more accepting of the fact that older adults are increasing in the number and rate of new HIV infections and AIDS diagnoses.

At this point, I can only speculate which of these social factors had a bigger influence on the (lack of) HIV/AIDS prevention education being provided to certain populations, especially older adults. However, they could certainly all be contributing factors to the funding and prevention education priorities of each state. The result does not change, as the findings reveal that older adults are being left out of HIV/AIDS prevention efforts in the Midwest.

### **The State of HIV/AIDS Prevention Education in the Midwest**

The findings from this dissertation project suggest that state HIV/AIDS policymakers and ASO personnel fail in their efforts to provide much needed information that would reduce the HIV/AIDS infection rate among older adults. However, it is not simply that they are adhering to sexual scripts about older adults, which influence them to believe that older adults are not at risk for infection for various reasons. While at times this is certainly the case, there are also other social

factors at play that result in older adults being left out of HIV/AIDS prevention education and health promotion in the Midwest.

After analyzing all of the data I collected, I believe that, while state HIV/AIDS policymakers and ASO do adhere to some sexual scripts about older adults, they are also critical of stereotypes about older adults and sexuality. This research also uncovered hints of physician influence over older adults, especially when it comes to HIV testing and prevention education. This is an important finding, given that older adults in the conservative Midwest would most likely be reluctant to seek out HIV/AIDS prevention education on their own unless it came from a medical authority figure with which they had a past history. Further, the fact that state policymakers and ASO personnel have to educate physicians and medical personnel about HIV/AIDS is a surprising revelation. If older adults are not being educated about their risk of HIV/AIDS infection when being prescribed Viagra or when discussing their sexual or drug histories with their physicians, they are probably not going to make an effort to seek out this information from an ASO or state agency. Physicians and other medical personnel certainly need to be educated about HIV/AIDS—especially how it manifests itself as normal signs of aging in older adults—in order to avoid misdiagnosing those who may already be infected, as well as to provide some form of prevention education to their patients if this epidemic has any chance of being slowed.

What became obvious as this research progressed was the importance of funding and the interconnectedness of political and economic factors with the

HIV/AIDS epidemic. Perhaps due to the enduring stigma of the disease, federal and state governments and governmental agencies appear reluctant to expand funding to sub-groups that are not the typical marginalized groups that are often associated with the epidemic (i.e., gay men, IDUs, and minorities). It is easier to provide funds to already-stigmatized groups than to admit that an older adult may need HIV/AIDS prevention education because he or she is having unprotected sex or injecting drugs. Because of this situation and the trickle-down effect of HIV/AIDS funding, ASOs have to restrict to whom they are able to provide prevention education. So if ASOs are not able to provide HIV/AIDS prevention education to older adults due to funding restrictions, and a large number of physicians are either refusing or are not educated enough about HIV/AIDS to provide education, from what source will older adults receive prevention education? This is the question that remains to be answered.

Despite this unanswered question, it is important to point out that this dissertation project has contributed to research in the area of sexual script theory and the sociology of risk. Gagnon and Simon (1973), who are the pioneers of sexual script theory, state that most people are blind to the fact that we follow scripts that define situations, labels and names of the actors, and the plots of behavior. For example, cultural sexual scripts, which are general guides to “normal” and “appropriate” sexual behaviors, are firmly entrenched in society and communities (Shoveller et al. 2004; Gott & Hinchliff 2003; Simon 1999; Gavey, McPhillips & Braun 1999).

But because sexuality is rarely anticipated in cultural scripts about older

adults, little research has been done on the sexual scripts about older adults. This dissertation has accomplished the task of exploring some of the consequences that common stereotypes and misconceptions of older adults and sexuality may have, such as a lack of HIV/AIDS prevention education for older adults. Further, this research highlights the result of the enforcement of these sexual scripts about older adults: an increase in the numbers and rate of HIV/AIDS infection among this particular population.

This dissertation project also expanded the area of risk, which Zinn (2006) points out there is comparatively little theoretical integration of into research. Risk is seen as the “likelihood or probability of some adverse effect of a hazard” and is scientifically measured and managed by both public and private domains (Short Jr. 1984). The U.S. HIV/AIDS epidemic was perhaps the first medical crisis in which stereotypes and blame contributed to an enduring stigma that was deemed more important than seeing it as a virus that needed to be cured (or at the very least, treated). HIV/AIDS was fixed in the public mind as the result of deviant behavior, and not as a virus that is transmitted through the exchange of bodily fluids.

Due to this complicated history, it appears difficult for our society to see anyone but those who are members of already-marginalized groups as being at risk for infection. It is clear from this research that older adults’ assumed lack of risk for HIV/AIDS infection is based on socially constructed misconceptions and stereotypes. Further, it became clear that these misconceptions and stereotypes influence individuals’ views about older adults, as may have been the case of physicians who

refused to provide HIV tests or prevention education to older adults or the respondents who laughed at the thought of older adults using Viagra.

The data I collected for this dissertation could have certainly been framed in different ways. For example, the focus of the dissertation could have been on the organizational culture of ASOs, the relationship between the states and the ASOs, the political economy of public health, and a myriad of other topics. However, I noticed a gap in the literature and on past and current research, and therefore I chose to examine the situation occurring with older adults and whether or not they are left out of HIV/AIDS prevention education. I felt as though, given the increase in rates and numbers of newly infected older adults, that I could attempt to understand the situation from a theoretical perspective, and also perhaps impact social policy in the Midwest.

This dissertation is not without limitations. As noted in Chapter Three, I encountered a few issues and challenges that, to some extent, had an affect on how I conducted my research and reported my findings. I was asking sensitive questions about a stigmatized disease, and the issue of confidentiality was especially important. Additionally, I was limited on who I could interview for this project due to the relative rarity of ASOs and the small amount of state policymakers in the area of HIV/AIDS. I was also asking the respondents questions that involved their opinions, which are very subjective in nature.

Despite these limitations, the research conducted in this dissertation has certainly opened the door to further research that I may perform in the future.

Because there is little research that has been done on the “Viagra factor” (the link between Viagra use and increasing numbers and rates of infections among older adults), this would be an area that is sure to generate interest. Another area of interest would be to perform an economic analysis of HIV/AIDS funding streams, including expanding on work being done on the cost/benefit analysis of prevention education. Finally, it would be interesting to see if the four comparison states (New York, California, Texas, and Florida) that are beginning to focus on older adults as a priority population are able to translate their recommendations in their state HIV/AIDS comprehensive plans into real prevention efforts and outcomes. Is social policy surrounding older adults and HIV/AIDS having an impact on the rates and numbers of infected older adults? These are all important research areas that grew out of this project and should be explored further.

In the conclusion chapter of this dissertation, I focus on the ever-changing status of ASOs in light of the current political and economic climate, and how older adults will be affected by these changes. I end this dissertation with an examination of the current and future impact that the increasing rate of HIV/AIDS infection will have on older adults, especially the fiscal cost of providing long-term HIV/AIDS care.

## **Chapter 7: Challenges Ahead**

From the data uncovered for this dissertation project, it is likely that older adults may continue to be off the HIV/AIDS radar for some time to come, especially in the Midwest. Existing cultural sexual scripts about older adults continue to influence those who decide who receives HIV/AIDS prevention education. As long as the stigma surrounding the HIV/AIDS epidemic continues to persist, a number of sub-groups within the general population may continue to be left out of prevention efforts and health promotions. ASOs are not currently in a position to slow the progression of the epidemic, and this, I argue, is due to problems within the funding system. There are specific resulting implications that the exclusion of older adults from HIV/AIDS prevention education will have, such as the cost of treating newly infected individuals and its impact on federal funding programs.

In this conclusion chapter of this dissertation, I examine the challenges that lay ahead that will continue to have an influence on HIV/AIDS prevention education efforts geared towards older adults. I focus on the ever-changing status of ASOs and funding for HIV/AIDS in light of the current political and economic climate, and how older adults will be affected by these changes. I also examine the current and future impact that the increasing rate of HIV/AIDS infection will have on older adults, especially the fiscal cost of providing long-term HIV/AIDS care.

### **The Future of the ASO**

Nutbeam (1997) states, “Health promotion is inherently political” (401). Nowhere is this more apparent than when looking at the economic and political

aspects of the AIDS epidemic that have long been intertwined. The political economy of the AIDS epidemic—including funding for research, education, and treatment—has shifted considerably based on the overall political climate of the U.S. during specific time periods (Nutbeam 1997). For example, little money was provided for HIV/AIDS research and treatment during the Reagan and (first) Bush years of the 1980s and early 1990s, but increased with the Clinton years during the 1990s. The political climate also stimulated issues of morality, something that has become increasingly apparent during the (second) Bush administration after 2001. As Thorogood (2002) points out, government-sponsored health education agencies and ASOs are facing a dilemma of providing much-needed information on a public health issue, while on the other hand having a political and social reluctance to raise the profile of a sex-related issue (especially in age cohorts that are thought not to have sex or be at risk for infection in the first place). As many an ASO found out during the past several years, issues of morality can be tied to funding, and fear of losing what little funding they have has contributed to this reluctance to put the spotlight on anything remotely involving sex.

The future of the ASO is certainly in flux as funding streams cannot keep up with the demands placed on them for testing, prevention education, and providing services to clients already infected. ASOs were not intended to be long-term care coordination organizations, but rather were to be emergency organizations which would provide services to infected individuals in their final days. As people are living longer with HIV/AIDS (thanks to scientific discoveries, such as the AIDS



cocktail and anti-retroviral drugs), they now require services for years rather than months. This increase in service use and service users has resulted in higher demands placed on ASOs who have limited resources (Cain 1997). Due to the fiscal constraints most ASOs face in dealing with a public health crisis on shoe-string budgets, many groups who were and continue to be at risk for HIV infection are left out of prevention and education campaigns aimed at reducing HIV risk.

Similarly, the Ryan White CARE Act (HR 4785)—a block grant which ASOs rely on for a significant portion of their funding—was originally enacted as a purely emergency fund to provide care for people with HIV or AIDS (THJKFF 2006d; Donovan 1997). The Ryan White Act has now been reauthorized three times since 1990 and reaches an estimated half million people in the U.S. with HIV and AIDS each year. Ryan White funds are the third largest source of public financing for HIV/AIDS behind Medicaid and Medicare and is the single largest federal program specifically designed for assisting people with HIV/AIDS. Currently an estimated 1.2 million people with HIV/AIDS receive Ryan White assistance (THJKFF 2007f).

These are dangerous times for ASOs, as critics are questioning how much longer federal funding should be provided to help fund ASO programs. The last reauthorization of the Ryan White CARE Act was contentious to say the least and surprisingly did not cut along partisan lines. The lines were drawn between elected officials who represented areas with the highest numbers of HIV and AIDS cases (i.e., California, New York, Florida, Texas, etc.) versus those who had a large proportion of their population test positive (the South and rural areas, for example)

(THJKFF 2006a). While in the past states with the largest volume of HIV and AIDS cases were given priority, the reauthorization of the Ryan White Care ACT in 2006 used a new formula in which larger amounts of the HIV/AIDS funding pot was diverted to those areas who had higher proportions of their overall populations testing positive. So while California and New York may be the traditional epicenters of the U.S. epidemic and have always had the highest number of cases, their share of the U.S. HIV/AIDS funding was being cut in order for other areas, states like Alabama and Mississippi, which are seeing an increase in the proportion of their residents who are testing positive for the virus. Hillary Rodham Clinton (D-NY) summed it up by stating that “You want to take money away from my 100,000 people living with HIV/AIDS and give it to worthy people in other parts of the country because this administration and this Congress won’t put more money into funding treatment programs for HIV and AIDS” (THJKFF 2006b). It is apparent from this last round of reauthorization that the HIV/AIDS funding pot continues to remain stagnant, even as the numbers and rates of the newly infected and those living with the disease continue to increase.

ASOs are also facing limited funds because, until recently, funding was based on the number of cases the state had, and how many people were diagnosed in that state. If a person tested positive in California but moved back to their home state of Idaho to live after they were tested, that person would be counted among California’s numbers. Because funding was determined based on the state’s numbers, where someone was tested was vitally important. This problem of where people get tested

was especially difficult for Midwestern states, which are considered as “come home” states for those who are infected with the virus (i.e., they find out they are infected while living elsewhere and return to their home/family to receive treatment or die). Therefore, the funding the four Midwestern states received over the last several years has not been enough to cover the number of people in their care.

While funding for Ryan White has seen considerable increases since its inception in 1990, this is not to say that Ryan White funds cover all needs. Because it is a discretionary federal grant program, funding depends on appropriations from Congress, and the amount of funding does not correspond to the cost of services or the number of people who need these services (THJKFF 2006d). While Ryan White funds remain about \$2.1 billion annually—less than 1% of the federal budget—more HIV-positive people are seeking treatment and living longer, making what would normally seem to be an adequate amount of funding less than is needed to meet the needs of all of those who are infected as well as to provide prevention to those who are not (THJKFF 2007f; THJKFF 2006g).

Why are Ryan White funds so controversial and why is more funding not being provided to ASOs? If it is simply a matter of treating a public health crisis, why is there a political fight about appropriating funds? I argue that the answer lies in the social construction of HIV/AIDS as a disease of those who practice immoral behaviors—sex (and gay sex at that), drug use, prostitution, etc.—and deserve the scourge of the disease because of these behaviors. The stigma attached to the epidemic has not diminished since the 1980s, and the thought of providing federal

funds for life-sustaining drugs to these marginalized individuals who exhibited personal irresponsibility or immoral behavior is perhaps too much for members of government and the general public to bear.

It would seem, then, that HIV/AIDS prevention education provided by ASOs would be the best solution to decreasing the number of newly infected individuals. Using prevention education as a way to control HIV/AIDS is not a new concept. From the beginning of the epidemic, researchers were calling for more education on how the virus was spread and what people could do to protect themselves from infection. Theoretically, risk reduction involves the adoption of new behaviors by a community, changing the social norms as a whole (Pinkerton, Kahn & Holtgrave 2002).

As the epidemic continues to advance in the general population, public health officials and ASOs will increasingly be called upon to provide prevention education (Lukenbill 1998). But even as some public officials are starting to call for more prevention (THJKFF 2007f), preventive measures have been, and continue to be, a low priority in medicine (Lawrence et al. 2003). Further, the CDC has no major federal proposals for the expansion of HIV prevention programs (Holtgrave & Pinkerton 2003). While research shows that prevention education campaigns do reduce high-risk behaviors (Prohaska et a. 1990), prevention programs only reach 1 in 5 of those individuals who need them (THJKFF 2005c). Based on the research, this lack of prevention programs is quite obvious in the older adult population. Due to a continued lack of HIV prevention education funding, older adults will most certainly

remain very low on the prevention priority list.

At the same time that the cost of treatment continues to rise and the amount of funding is becoming even more inadequate, HIV/AIDS is taking on the characteristics of a long-term, chronic disease. It is becoming even more apparent that prevention is an extremely important concept. As Pinkerton, Kahn, and Holtgrave (2002) tell us, “The old adage ‘an ounce of prevention is worth a pound of cure’ has never been truer” (175). However, when it comes to federal funding for prevention, “Prevention funding has always been a ‘poor cousin’ in the hierarchy of domestic HIV-related discretionary spending” (Levi 2003: 126), with biomedical research receiving the highest level of funding.

Investment in prevention education and health promotion seems to require evidence that future savings in health and social costs will offset the cost of prevention. In the case of HIV/AIDS, the lack of a national healthcare system means that any effort to use prevention education through the public health program would require massive sums of health-care dollars and the coordination of prevention programs through the national government (Kaufman 1998). Ultimately, prevention has not been more effective due to insufficient resources, prevention burnout, political views, and the stigma associated with the virus (Holtgrave 2003). Therefore, prevention remains low on the government’s financial priority list and responsibility for prevention behaviors and education falls upon individuals. As Gordon (1993) states,

Public health continues to be difficult to sell, whereas health care continues to be demanded and better funded. Public health programs, unlike health care

issues, lack an effective constituency. Public health has always been a rocky road, as it provides no immediate gratification or feedback. It requires the ability to look to the future, which is not a commonplace trait of our political leaders who are looking to the next election rather than the status of their constituents' health in coming decades. Public health, thus far, lacks the glamour associated with hospitals, organ transplants, emergency medicine, diagnosis, treatment and rehabilitation and does not compete well with crisis health care (263).

There are some critics who do not believe that HIV/AIDS prevention programs are even necessary, that is ultimately the responsibility of an individual to curb their own risk behaviors. While opponents might point out that AIDS receives the most government money spent on any disease while other diseases are virtually ignored—ABC's John Stossel, for example, so famously pointed this out during a television broadcast in 1999 (Fairness & Accuracy in Reporting 1999)—this statement does not tell the full story. Research shows that government funding is allocated based on different criteria, such as public health needs, the probability of success with the research, and the quality of the research (Gross, Anderson & Powe 1999; Varmus 1999). Among diseases, the prevalence and incidence of the disease is considered, but the cost and degree of suffering is also taken into account with funding decisions. Further, the disability-adjusted life-years of a particular disease is also strongly associated with funding decisions, as the age of the infected, the degree of disability, and the number of deaths all impact health-care costs and loss of productivity to society.

In order to measure the force HIV and AIDS has on society, the medical field, and the labor market, the most appropriate choice of measurement is in life years lost. Conversely, prevention programs can be measured by life-years saved, or the number

of averted HIV infections (Trentacoste et al. 2004; Pinkerton, Kahn & Holtgrave 2002). The classic meaning of risk stems from economics (Heimer 1988), so basing prevention on the overall cost to society and a potential loss of productivity has been used to determine the probable risk to the population as whole (Bozzette 2005). At its peak, the epidemic accounted for 7% of the total potential years of life lost in the US, more than many diseases combined (Bozzette et al. 1998), and was even more dramatic in cities and states that had large numbers of infected residents (Obiri et al. 1998).

Using this measurement certainly puts the epidemic into perspective, but might not be a convincing argument to provide more funding for HIV/AIDS prevention education for older adults. Not only would it require our culture to accept that older adults or pre-retirement and post-retirement age are, in fact, in need of prevention education, but it would also mean that other stereotypes about older adults—that their lives are not worth saving because of their advanced age, for example—would have to be dispelled. These are the obstacles that ASOs who are just struggling to cover their basic operating needs will have to overcome to fully address the rising problem of HIV/AIDS among the older adult population.

### **The Impact on Older Adults**

A number of older adults will certainly experience the implications of this funding crisis at the federal government, state, and ASO level. Without a concerted effort to provide HIV/AIDS prevention education to other segments of the population in addition to the traditional “risk” groups, there is a real possibility that the U.S. will

continue to see an increase in the numbers of new infections among older adults. Ideally, HIV/AIDS prevention education would be provided to all of the U.S. population, as everyone who participates in certain behaviors are putting themselves at risk for infection. However, the fact that older adults lack the most information about HIV/AIDS among all age groups (Altschuler, Katz & Tynan 2004), are less likely to be tested or to use condoms than any other age group (Orel, Wright & Wagner 2004), and are still having sex (Lindau et al. 2007; AARP 2005) (even in nursing homes and assisted living facilities) means that older adults are a particularly vulnerable population.

A compelling reason for federal and state governments to consider providing HIV/AIDS prevention education to older adults is financial. Though not unique to older adults alone, the financial stress of HIV can be an even larger burden to older adults who are more likely to be low-income and have co-morbidity issues (Vance & Robinson 2004). Medicare—the federal health insurance program that covers older adults over 65 and those who are disabled due to HIV/AIDS—is the second largest source of U.S. federal spending for HIV/AIDS-related care (THJKFF 2005a). Seventeen percent of all Medicare beneficiaries with HIV/AIDS fall into the target population of 50 or older, and is expected to rise substantially as this population increases. Further, Medicare is currently the payer of choice for individuals who are on antiretroviral and other HIV/AIDS related drugs, which run between \$2,000 and \$4,700 per month (Schackman et al. 2006). As a result, the Medicare program will increasingly be called upon to pay for treatment for newly infected older adults and



older adults who have aged into older adulthood already infected.

Medicaid—the federal health program for low-income adults—faces the same financial dilemma as Medicare. Medicaid’s role in the rise of HIV/AIDS among older adults has already been well established due to the fact that a large proportion of this population who are infected are low-income or become disabled due to HIV/AIDS-related illnesses. Medicaid funds are also used to purchase prescription drugs for eligible recipients (THJKFF 2005b).

As the numbers of HIV/AIDS infected older adults continues to increase, more Medicare and Medicaid funding will have to be provided to those infected older adults who qualify for expensive HIV/AIDS medical services. The current estimates for treating HIV over the course of a lifetime are expected to increase from the 2004 yearly estimate of \$618,900 (Schackman et al. 2006) to closer to the \$1 million range when including the loss of economic productivity in addition to medical treatment costs (Pinkerton, Kahn & Holtgrave 2002). The exorbitant cost of HIV/AIDS drugs and other treatment has resulted in a crisis for some private insurers who are reluctant to cover any costs associated with HIV/AIDS (Schackman et al. 2006). Further, as antiretroviral and other HIV/AIDS drugs continue to extend the life of infected individuals, the long-term care of older adults who are infected will increasingly become an issue that assisted living facilities and nursing homes will face. The issue of federal and state funding to support those who are infected takes on even greater importance when considering these long-term costs.

The rising cost of treating HIV/AIDS could result in a financial crisis for the

U.S. and individual states, all of whom are already facing tighter budgets and limited Medicaid and Medicare spending. Ultimately HIV prevention efforts and health promotion could be more cost-effective and cost-saving to each state. A new study by Sanders, Bayoumi, Holodniy, and Owens (2008) reveals that HIV/AIDS testing for people ages 55 and older was found to be extremely valuable and necessary in terms of the potential savings in health care costs and the years of life gained from an early diagnosis. However, prevention education for HIV/AIDS in the older adult population has not been realized in any of the states studied in this dissertation. Federal public education outreach campaigns, tailored and targeted HIV/AIDS prevention messages for older adults, ASO community outreach for older adults, and working with Area Agencies on Aging and senior centers would all have the potential to prevent new infections among the older adult population. However, these all require significant funding support and an acceptance of the fact that older adults are at risk for HIV infection, both of which many in power are not willing to provide. Further, the question of how to reach older adults of pre-retirement ages—those who are not likely to frequent senior centers or Area Agencies on Aging—remains a difficult challenge.

Based on my research of HIV/AIDS service organizations and state involvement in the epidemic, my conclusion is that HIV/AIDS has been turned into a bureaucratic problem instead of a purely health-related problem, and social constructs—prevailing sexual scripts, the enduring stigma of HIV/AIDS, and the construction of risk groups—only complicate the situation. I conclude that older

adults, a group who comprises the next "big" HIV/AIDS risk group, inevitably fall between the prevention education cracks of public health. The lack of federal and state funding, enduring sexual scripts, risky sexual behavior, and the continuing stigma associated with HIV/AIDS combine as a force, resulting in ASOs only being able to deal with the most at-risk group that they can fiscally and bureaucratically manage to serve, while other at-risk groups fall by the wayside. The “problem” of older adults and HIV/AIDS is a bureaucratic and social predicament with a looming challenge to the U.S. public health system.

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