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HIV/AIDS Policies in the United States and the United Kingdom: Emerging At-risk Groups and the Struggle for Limited Resources

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HIV/AIDS POLICIES IN THE UNITED STATES AND THE UNITED KINGDOM:
EMERGING AT-RISK GROUPS AND THE STRUGGLE FOR LIMITED
RESOURCES

by

Jennifer Lorren Willis

A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
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Jennifer Lorren Willis

HIV/AIDS POLICIES IN THE UNITED STATES AND THE UNITED KINGDOM: EMERGING AT-RISK GROUPS AND THE STRUGGLE FOR LIMITED RESOURCES

Jennifer Lorren Willis, M.A.

Western Michigan University, 2007

This thesis compares the HIV/AIDS policies in the United States of America and the United Kingdom since the emergence of the virus in 1981. Despite a privatized health care system in the U.S. and the universal system in the UK, which lie on opposite ends of the policy care spectrum, similar populations have recently emerged as those most in need of health care services, preventative programs, and financial assistance. This thesis employs several quantitative and qualitative data to highlight the emergence of women and minorities in both nations as those that are most in need of resources. Data has been collected from archives, articles, and published reports.

This thesis explores the reasons for the emergence of similar groups despite the difference in health care and political systems. In the U.S., an active and politically powerful lobby of homosexual groups and hemophiliacs, which were the first to be affected by the epidemic, have blocked resources to emerging groups. In the UK, the lack of access to officials, and a heavy reliance on the universal health care system, has prevented new at-risk populations from receiving the specialized care necessary to prevent the spread of the epidemic.

TABLE OF CONTENTS

ACKNOWLEDGMENTS	ii
LIST OF FIGURES	iv
I. INTRODUCTION	1
II. RESEARCH DESIGN	4
Hypothesis	5
Case Selection	6
III. LITERATURE REVIEW	9
IV. OVERVIEW OF GOVERNMENT STRUCTURES	14
British Government Structure	14
U.S. Government Structure	17
V. OVERVIEW OF HEALTH CARE POLICIES	21
Health Care Policy Options	21
The UK Health Care System	24
The U.S. Health Care System	31
VI. AIDS POLICY OVERVIEW	43
HIV/AIDS Drugs	51
VII. PROSPECTS FOR ADDRESSING THE NEEDS OF EMERGING AT-RISK GROUPS AND CONCLUSIONS	59
Conclusions	65
BIBLIOGRAPHY	66

LIST OF FIGURES

1. The Structure of the U.S. Department of Health and Human Services (HHS.gov).....	33
2. Flow of Health Care Financing in the U.S., 2003.....	35
3. Title I Allocation.....	49

CHAPTER I

INTRODUCTION

Public health care is a relatively new policy that emerged in the United States and most Western European nations during the period of industrialization and flourished after WWII. Since the implementation of basic health care provisions such as the clean water and air acts, health education, and food and drug regulation, industrialized nations have varied widely on their policies toward curative care and preventative care. Who should have access to medical care, and at what costs, are arguably the most fundamental debates of current health care policy in North America and Europe (Graig, 1999).

While nations continue to address these policy questions, new diseases are continually emerging. These diseases test the capabilities of health care systems and provide insight into how nations design and implement health care policies. One such infectious disease is the Human Immunodeficiency Virus (HIV), which causes Acquired Immune Deficiency Syndrome (AIDS). Symptoms of what would later be termed AIDS were found in homosexual males in the United States and Sweden, and in heterosexual males in Tanzania and Haiti, in the late 1970s and early 1980s (avert.org; cdc.gov; Siplon, 1999). Since then, AIDS has taken on epidemic proportions. There have been various responses to this threat by both public and private institutions.

HIV/AIDS is not unique in that it is a disease which requires governmental intervention. "AIDS is a communicable disease and prevention and treatment of communicable diseases have a history of being defined at least partially as the responsibility of the government" (Siplon 2002, p.1). While governments may be responsible for prevention and intervention, the extent to which the government must

secure access to resources is still debatable. All public policy involves the distribution and redistributions of resources including money, decision-making authority and attention. Policy also reflects the values of a society and the way that society views a problem or group.

In regard to HIV/AIDS policy it would seem that, at least initially, this distribution would take one of two routes: Either decide what group needs resources the most, or give resources to groups according to infection rates. “The reality is very different. What is at issue is more than how to most expeditiously stop the transmission of a virus. The communities are seeking to validate and preserve values and ways of living” (Siplon 2002, p.4-5). The communities involved include uninfected citizens, affected populations, government officials, the medical community, and various corporations. All these groups have a stake in HIV/AIDS policy, intervention and prevention.

The emphasis of this work is to address emerging at-risk groups in the U.S. and the UK, discuss the prospects for treating these groups, and assess what factors will account for the differences in those prospects. Chapter II discusses my research design, hypothesis, and case selection. Chapter III outlines the theoretical approaches relevant to health care policy. Chapter IV provides a brief overview of British and U.S. government structures. Chapter V gives a brief overview of health care policy options, and then focuses on the health care systems of the United States and the United Kingdom. This chapter also presents a brief summary of health care reforms in the two nations. Chapter VI focuses on HIV/AIDS policy with a section specifically highlighting HIV/AIDS drugs

and the role of medications in HIV/AIDS policy. Chapter VII discusses the prospects for addressing the needs of emerging at-risk client groups and also offers my conclusions.

CHAPTER II

RESEARCH DESIGN

This thesis examines why similar at-risk groups emerged in the U.S. and the UK despite different governmental structures, health care systems, and HIV/AIDS policies. I will be using a literature review and secondary research to examine not only why similar groups emerged, but what the prospects for receiving care are for these groups in each nation. My research will focus on comparing HIV/AIDS policies in Great Britain and the United States since 1981. Both nations have been able to increase political and medical access to groups affected by HIV/AIDS through policy initiatives (Siplon, 1999). The Department of Health's Sexual Health and HIV Strategy Action Plan in Great Britain and the Ryan White CARE Act in the United States are two examples of initiatives designed to specifically aid HIV/AIDS infected persons, and target at-risk populations for preventative measures.

The UK's program and the USA's legislation were both originally targeted at populations in which the disease first emerged, such as hemophiliacs and homosexual men (Rundall et al, 2005; Department of Health, UK site); however, new populations are emerging as those increasingly affected by HIV/AIDS (Rundall et al, 2005; DH, UK site). Currently, those who are increasingly at risk in both Great Britain and the United States are heterosexual women and minorities (Siplon, 1999; Rundall et al, 2005; www.dh.gov.uk). My research will compare these two nations and how their political and medical systems provide access and care for these emerging at-risk groups.

I am focusing on the Ryan White CARE Act of 1990 (re-authorized in 1996 and 2000) in the United States specifically since it provides an instance of a federal initiative

and federal funding to specific cities, all 50 states, and target populations. In Great Britain I am analyzing the Department of Health's Sexual Health and HIV Strategy which was presented in 2001 to improve the health and social care of those living with HIV. This was the first NHS strategy specifically designed to combat the HIV/AIDS epidemic in England. I am highlighting the emergence and prevalence of at-risk groups such as women and minorities in both nations and examining which nation will be able to provide these emerging infected groups with modern health care and preventative education.

Hypothesis

Although the Ryan White CARE Act and the UK's Sexual Health and HIV Strategy increased education, access to care, and funds for HIV/AIDS organizations, neither country has performed well in preventing infections and educating emerging at-risk groups such as minorities and heterosexual women as of 2004 when compared to nations such as the Netherlands, which instituted harm reduction strategies in 1984 (Worldbank.org, 2006). However, both countries have obviously prevented the spread of HIV/AIDS substantially better than developing nations such as those in Sub-Saharan Africa, and more recently Latin America, where HIV/AIDS rates have continued at epidemic proportions (UNAIDS.org, 2006). I will demonstrate the emergence and prevalence of HIV/AIDS in these populations and how they have become more pronounced over time. My hypothesis is that certain factors characteristic of the UK will make it more likely for at-risk groups to gain access to HIV/AIDS funds, education and health care.

The first factor is the difference in governmental structures and institutions; particularly the UK's unitary, parliamentary system versus the USA's federal, presidential system. The presence of multiple veto points and multiple veto players make the U.S. less likely to pass legislation, and even less likely to pass legislation quickly. This may lead to problems when trying to stop, treat and educate the public to an epidemic. In contrast, the lack of multiple veto points and players in the UK allow that nation's government to allocate funds to treatment and education with greater ease than the U.S. (Crepaz, 1998; Huber et al., 2003; Tsebelis, 1995). Second, is the lack of a cohesive gay community in the UK in contrast to the prominent and well organized gay movement in the USA. My final point is that the lack of a national health system in the U.S. inherently leaves certain populations without medical coverage, and without proper medical care these population are at a greater risk of ill sexual health.

Case Selection

I selected these two cases for several reasons. The U.S. has arguably been the industrialized nation most affected by HIV/AIDS in terms of infections (womenshealth.gov). The first instances of AIDS in the U.S. were diagnosed in the early 1980s and ever since private groups, followed later by the U.S. government, have been active in seeking treatments and a cure. Although the UK is a predominantly Caucasian nation, it is more ethnically diverse than most western European countries, which makes this particular research design somewhat more feasible. In addition, the UK and U.S. are usually identified in the same political-culture group, i.e. that of Anglo-Saxon, liberal democracies (Moe and Caldwell, 1994).

I also focused on the UK because HIV/AIDS was significant enough to draw national attention and lead to a specific action plan, whereas in other Western European countries HIV/AIDS policies were simply incorporated into the existing health care system due to the very limited number of infections. Both nations saw private groups take the initial steps to providing care, support and education to victims. One notable difference in policy is that the U.S. designed its first national HIV/AIDS program in the 1990s while officials in the UK provided funds to particular ad campaigns and organizations until their first national strategy in 2001 (Small, 1993; Siplon, 2002).

There are a couple possible reasons for this disparity, the first being that lobbying efforts by U.S. interest groups were much more effective at drawing attention to the HIV/AIDS epidemic. Another possible answer is that HIV/AIDS patients were included into the British National Health Service with relative ease initially, but without acknowledging the need to create a nation-wide prevention and educational campaign. A third explanation is the election of Tony Blair and the Labour party in 1997, which caused a major policy shift when compared to the Conservative governments of former Prime Ministers Margaret Thatcher and John Major.

There are also strong and unique historical, cultural, and linguistic ties between the United States and the United Kingdom (Theodoulou, 2002). Finally, I chose these two nations due to the fact that the clinical, scientific, and medical standards of both are similar. In addition, each the medical communities in each country frequently read and refer to the medical publications of the other (Aaron et al, 2005).

Although I selected these two nations for their similarities in regard to HIV/AIDS, I also chose these nations for their numerous structural and institutional differences. The

U.S. maintains a presidential system, while the UK boasts a parliamentary (Westminster) system. The U.S. also contains a bicameral legislature, undisciplined parties, appointed bureaucracies, and the presence of a strong Supreme Court. In contrast, the UK is (de facto) unicameral, possesses disciplined parties, independent bureaucracies, and lacks a strong supreme court (Tsebelis, 1995; Huber and Stephens, 2001). In addition, to the differences in governmental structures, the configuration of interest groups and the presence of a national health care system in the UK and a mainly private health care system in the USA have effected how these two nations approached HIV/AIDS. These disparities offer insight into how two nations which have very different institutions approach a common problem.

CHAPTER III

LITERATURE REVIEW

There are a variety of competing theories which attempt to explain the presence and extent of health care in industrialized nations. Cultural explanations have focused on individualistic and antigovernment cultures, particularly in the U.S., as the reason why access to health care remains limited. The argument states that Americans despise government involvement in most areas of their lives, and feel that anyone can be successful if they work hard enough. This theory also hypothesizes that Americans in particular are opposed to health care programs that cover a majority of the population because this type of policy would be representative of socialism (Giaimo, 2002; Graig, 1999).

The New Right – a loose term that encompassed market liberals and social conservatives – viewed postwar capitalist settlements and their associated social programs as harmful to the capitalist economy and liberal democracy. Neoliberals argued that the welfare state siphoned off funds into consumption that could have gone into productive investment, thereby stunting economic growth. Social conservatives believed that welfare programs created disincentives to work and encouraged dependency (Giaimo, 2002, p. 22).

These explanations have limited power, particularly in the field of health care policy. For example, when Bill Clinton took office in 1992, many people agreed there was a health care emergency which would require significant, if not radical reform (Giaimo, 2002; Theodoulou, 2002). In fact, “75% of Americans support health care

reform even if it means higher taxes” (Theodoulou, 2002, pg. 171). In addition, cultural arguments have difficulties accounting for differences in policies when using cross-national comparisons of culturally-similar nations. This is particularly evident when comparing the U.S. to Canada or Great Britain.

A related theory, which is relevant in much of the HIV/AIDS literature, is social construction. Social construction theory focuses on “assigning meaning to the condition, including all that is implied in calling it a disease, in a broader framework of traditional meanings, appealing metaphors, and convincing theories” (Schroedel and Jordan, 1998). Schneider and Ingram’s theory of social constructions of target populations refers “to the cultural characteristics or popular images of the persons or groups whose behavior and well-being are affected by public policy” (Schneider and Ingram, 1993).

In regard to HIV/AIDS policy it follows that certain positively constructed, politically powerful groups, such as hemophiliacs and blood transfusion patients who are often referred to as “victims” or “real victims”, will receive the most benefits from legislation, including funding for health care treatments, compensation, and greater access to officials. On the other hand, negatively constructed, politically weak groups, such as prison inmates and intravenous drug users, will receive the bulk of policy burdens including the absence of a strong lobbying organization, less education efforts, no compensation, and greater costs in health care treatments.

Economic explanations of health care policy have focused on a desire to control costs, as well as Wilensky’s convergence thesis. The convergence thesis states that as countries become more industrialized they are likely to experience similar social and political pressures, which often result in the adoption of similar policies (Wilensky 1995).

While costs have been a factor for all industrialized nations, countries with the ability to exercise more control over health care practices, such as Great Britain, are able to implement better cost control measures than nations like the USA, and thus are not as constrained by national health care expenditures. We also find a lack of applicability in the convergence thesis, especially when comparing the U.S. and UK. The U.S. and UK likely felt similar social and political pressures, especially due the effects of major, shared events like WWII; however, these similar pressures resulted in creating two health care systems which are on completely different sides of the health care policy spectrum.

Political theories, particularly power resources theories, are quite strong when analyzing health care policies. In particular, the presence of a strong single interest group – the medical profession, can be crucial in health care policy making. We see this clearly in the United States where the American Medical Association (AMA) has been able to effectively pursue and promote its own interests, arguably at the expense of other groups such as the elderly and the uninsured.

In the professional model of governance in the United States, the AMA and its state and local counterparts were powerful actors in policy formulation and in sectoral administration. But that power did not derive from an officially sanctioned insider status in negotiating policy. Rather, the AMA's influence in the political arena lay in its ability to marshal its considerable resources to engage in classic pressure group tactic, such as lobbying lawmakers, financing campaigns, and forging strategic alliances with other health care stakeholders to defeat legislation that threatened its vision of professional autonomy (Giaino, 2002, p. 15).

This example also applies to the UK, where a division in the British Medical Association (BMA), between general practitioners and specialists, created room for other groups to successfully lobby (Small 1999).

Other political explanations focus on the effects of regime legacies and the ratchet effect. Regime legacies refer to the effects of one group or party controlling the policy agenda for a period of time, “affecting the distribution of preferences, which forecloses some opportunities and opens others” (Huber and Stephens, 2001). The policy ratchet effect states that it is rare for a party to roll back certain reforms issued by the previous party in control if those policies had mass appeal. The effect is that policies shift closer to the center (Huber and Stephens, 2001). All three of these political theories provide important insights to the health care policy debate.

A final theoretical school focuses on institutional explanations of public policies. In the social sciences, it has become evident that institutions matter (Crepaz, 1998). “Independently of partisan coloration, some governments have more room to maneuver than others; some are more effective in pushing through various policies, while others are more accountable to their citizens” (Crepaz, 1998, p. 61). The organization of the government as federal or unitary, parliamentary versus presidential, unicameral or bicameral, may create varying numbers of institutional veto points. In addition, the presence of appointed versus independent bureaucracies, disciplined or undisciplined parties, or a strong supreme court affects the number of veto points involved in the legislation process. Institutional veto points are “strategic points of uncertainty that arise from the logic of the decision making process itself” (Immergut, 1992); “if any proposal for policy change is to succeed and pass into law, it must win support at all of these

points, because the occupants of these institutions wield veto power over such proposals” (MacIntyre, 1999; O’Reilly, 2005). The greater the number of veto points, the less the chance of sweeping reforms (Crepaz, 1998; Tsebelis, 1995).

Where political authority and decision making are centralized, as in unitary and Westminster parliamentary systems, enactment of controversial legislation tends to be easier than in federal or presidential systems where dispersed decision-making structures provide opponents with multiple veto points (Immergut, 1992; Giaimo, 2002, p. 26).

When examining the U.S. and UK we see that institutional theories which focus on veto points have substantial explanatory power. Veto points theory has been tested in areas such as social welfare policy (Crepaz, 2002), legislative output (Tsebelis, 1999), taxations policy (Hallerberg and Basinger, 1998), and more recently foreign economic policy (O’Reilly, 2005). I am predominantly employing this theory to show that while certain groups may be able to benefit from public health policies, emerging at-risk groups have a more difficult time receiving aid and policy benefits according to the organization of the government and the number of access points available to emerging groups. I will highlight the importance of veto points during the examination of health care reform legislation in each nation.

CHAPTER IV

OVERVIEW OF GOVERNMENT STRUCTURES

British Government Structure

Great Britain is a parliamentary democracy with a constitutional monarch, Queen Elizabeth II. The Queen's duties are mainly limited to her titles (head of state and the executive branch, the head of the judiciary, commander-in-chief of the armed forces, and 'supreme governor' of the Church of England), as the Queen is uninvolved in the day-to-day operations of the government (Britannia, 2006). The stability of the British government can be attributed to the monarchy, which has only been interrupted once (the republic of 1649-60) in over 1,600 years (Britannia, 2006). The British constitution is not contained in a single document, rather it is comprised of several laws, customs and practices which are not legally binding, but considered essential to the functioning of the government. These documents include the Magna Carta (1215), the Petition of Rights (1628), and the 1689 Bill of Rights. The advantages to not having a written constitution like the USA is that it provides greater flexibility since "it can be amended through the same process as ordinary laws" (Madgurck and Woodhouse, 1995; Theodoulou, 2002, p. 49).

Power in the United Kingdom emanates from the Westminster Parliament (Theodoulou, 2002). Regional governments exist, but are subordinate to this central power and are not granted any powers by the British Constitution. The legislative branch of government consists of the Parliament which contains the House of Commons, the House of Lords, and the Queen in her constitutional function. This makes Parliament the supreme legislative, executive, and judiciary authority (Bogdanor, 1988, p. 55). There

are 646 Members of Parliament (MPs) which represent local constituencies throughout the England. Power is concentrated in the House of Commons while the House of Lords acts mainly as an advising chamber. The main functions of the House of Commons are representation, legislation, scrutiny of government, and as “a forum for national debate” (Theodoulou, 2002). The House of Commons may also force a government to resign through a vote of no confidence, but it rarely exercises this function due to the disciplined nature of British political parties.

The House of Lords follows the principle that it should compliment the House of Commons, not rival it (Britannia, 2006). The House of Lords does not have any veto powers over legislation it can only “delay most legislation for a year, and financial legislation for only a month” (Tsebelis, 1995). Frequently, this asymmetric legislature leads researchers to group the UK as being defacto unicameral (Lijphart, 1992).

There are two main political parties in the UK, the Conservative Party and the Labour Party, as well as several minor parties including the Liberal Democrats, Plaid Cymru (the Party of Wales), and the Scottish National Party, which are represented in the Parliament. Although there are multiple parties represented in the Parliament, the UK has a distinct two-party system. The Prime Minister (PM) is the leader of the political party that gains a majority in parliamentary elections, and is responsible for directing and coordinating the work of the government. The PM often dictates the agenda of the government, and has the power to dissolve the government and call for general elections as he or she sees fit. As a formality, the Queen appoints the leader of the party with majority support in the House of Commons as Prime Minister. The Prime Minister is the acting Head of Government and thus is responsible for appointing about 100

representatives from the general parliament to serve as departmental ministers. Twenty of these ministers make up the Prime Minister's Cabinet. The minority party in Parliament also selects a leader who then appoints a 'shadow cabinet' (Theodoulou, 2002; Britannia, 2006). One of these senior Cabinet positions is the Secretary of State for Health which is head of the Department of Health.

The policy making process in the UK is fairly straightforward due to the fact that power is concentrated with the PM and the cabinet. "The PM has a direct relationship with all ministers and is informed of all new policy initiatives. This allows the PM to dominate policy making for he or she can use the powers of their office to decide which policy should proceed and which should be dropped" (Theodoulou, 2002, p. 57). Before policy initiatives are brought before the PM and the Parliament, the civil service under the guidance of ministers formulate policy through close relationships with interest groups and/or local governments. Parliament's role in the policy process is essentially to scrutinize policy details and adopt the new legislations, possibly with amendments attached. "British public policy is normally then worked out through a process that emphasizes consensus and consultation with affected interests. Civil servants, ministers, and representatives of special sectional interests cooperate with each other when policy is formulated" (Theodoulou, 2002, p. 57).

Although this highly secretive process seemingly excludes the public, party competition "encourages policy innovation and the attempt to impose a consensus. Parties have a vital interest in ensuring that when each is not in government the new government does not repeal its old policies" (Theodoulou, 2002, p. 58). When examining this process it becomes apparent that there is only one major veto point in the British

parliamentary system (Tsebelis, 1995). “In fact, common complaints in the United Kingdom concern frequent policy reversals and adversarial ‘stop and go’ policies, while in the United States the standard argument revolves around divided government and gridlock” (Tsebelis, 1995, p. 316).

U.S. Government Structure

The United States of America is a constitutional, democratic, federal republic. The government is divided at the local, state and national level. At the national level, power is distributed between three branches; the executive branch, which carries out the laws; the legislative branch, which creates and passes the laws; and the judicial branch which interprets the laws. The first two branches have been crucial to developing HIV/AIDS policy while the judicial branch has been less active; its functions have mainly been limited to defining what constitutes AIDS related discrimination (Siplon p. 9, 2002).

In contrast to the UK, the United States does have a formal, written constitution. The U.S. Constitution was ratified in 1788 and is the “oldest such document in continuous use in the world today (Theodoulou, 2002, p. 88). The Constitution gave the national government powers over the states in matters such as currency, foreign affairs, national defense, and reserved other powers to the states such as police, and public safety. The Constitution organizes the government with four basic principles: federalism, separation of powers, checks and balances, and the supremacy clause, which makes the Constitution’s laws superior to the laws of the states.

The executive branch is headed by the President, who acts as American Head of State, Chief of the Government, and Commander-in-Chief of the armed forces, and the

Vice President who acts as President of the Senate. The President of the United States is also able to issue executive orders, veto and sign laws, and influence public opinion.

“Presidential power has grown tremendously since the first days of the nation’s inception” (Theodoulou, 2002, p. 90). Presidents serve fixed four year terms and the 22nd Amendment limits those terms to two. The President is the chief legislator in the country and the public has “come to expect a policy agenda from it presidents (Theodoulou, 2002, p. 89). Presidential power is limited by the Constitution, Congress, the Supreme Court, and more informally by the media and public opinion. Although not mentioned in the U.S. Constitution, the President also has a Cabinet consisting of the heads of federal executive departments. The Secretary of Health and Human Services (HHS) is one of 14 department heads which report to the President.

The legislative branch is controlled by a bicameral Congress consisting of the Senate (100 seats, one-third are renewed every two years; two members are elected from each state by popular vote to serve six-year terms) and the House of Representatives (435 seats; members are directly elected by popular vote to serve two-year terms) (cia.gov, 2006). In the U.S. Constitution congress was delegated powers to act as the dominant branch of government. This has not been the case in the 20th century with the Congress instead using its legislative functions to refine presidential policy initiatives (Theodoulou, 2002, p. 90). Legislation is introduced in one of the houses in the form of a bill. It is then sent to a legislative committee for debate, denial, or approval (Theodoulou, 2002, p. 92). In order for a bill to become a law in the USA, it must be passed in the same form by the Senate and the House. It then must be signed by the President. If the President

does not sign the bill and chooses instead to veto it, the Congress can still pass the law with a 2/3 majority vote in both houses.

The U.S. judicial system is based on English common law, and is the weakest on the three branches of government for multiple reasons including: justices are appointed to life terms by the president and confirmed by the Senate, and the judiciary must rely on the executive to enforce their rulings. The Supreme Court is the highest court in the U.S. judicial system. It is composed of nine justices who are appointed “for life on condition of good behavior by the president with confirmation by the Senate” (cia.gov, 2006). “The judicial branch, through the Supreme Court has become a controversial actor within the policy-making process. It is argued that by passing judgements on what is constitutional, it sets policy agendas” (Theodoulou, 2002, p. 92).

State governments in the U.S. have significantly more authority than regional governments in the UK since all authority not delegated to the federal government by the constitution is given to the states. If there is a dispute over jurisdiction it is up to the federal judiciary to decide the intent of the Constitution. “State governments can help in contemporary policy making apart from implementing broad national policy objectives. At the state and local level, experimentation may take place. The cost of failure at the local level is much less than if a national policy was implemented” (Theodoulou, 2002, p. 94).

Due to the decentralized nature of the U.S. system, there are multiple points of access, and conversely multiple point of blockage. Tsebelis defines the U.S. as having three major institutional veto points (both houses of Congress and the President) in contrast to the UK’s singular veto point (Tsebelis, 1995, p. 316). There are advantages to

such a fragmented system including full deliberation of issues, increased input and diversity of ideas, and the protection of individual rights. However, it can be impossible to reach a policy outcome on an issue. “Such decentralization causes unwieldiness, redundancy, and often a slow-moving response to issues and problems. However, it is also a way to represent the diversity of such a large nation as the United States” (Theodoulou, 2002, p.93).

Other disadvantages include conflicting policies, especially at the state and local levels, the representation of too many interests which leads to incoherent policy, and problems of implementation. This is especially true of controversial issues or those dealing with controversial or under-represented groups such as the case with HIV/AIDS legislation. It is within this context that we look at health care policy, and more specifically HIV/AIDS policies.

CHAPTER V

OVERVIEW OF HEALTH CARE POLICIES

According to Stella Theodoulou, the goals of health care policy are “to promote and attain good health, (and) to provide the adequate or satisfactory conditions that good health requires” (Theodoulou, 2002). Welfare policy that does not adequately provide a safety net for its citizens and where all regardless of status are not guaranteed income, housing or safety, will undermine any type of direct medical provisions” (Theodoulou, 2002, pg. 134). There is little doubt that public health is important to industrialized nations. Healthy people are more productive in the workplace and are better able to “maintain their living conditions and raise healthy families” (Theodoulou, 2002). Thus, the U.S. and UK both provide basic public health services such as health education in schools, public health service announcements through broadcast media outlets, vaccination programs, sanitation programs, and the regulation of food and drug quality.

Health Care Policy Options

There are several ways to classify health care systems found in industrialized nations. These models provide a general idea of how certain systems function, but are “limited by the fact that no pure version of any of the systems exists” (Graig, 1999, p. 2). Most health care systems combine elements of public and private models, since “all countries are searching for what they believe is an optimal mix of public and private activity” (Adolino and Blake, 2001, p. 209). Laurene Graig provides one such method of classification:

1. *national health service model* (also known as the Beveridge model), characterized by universal coverage, general tax-based financing, and national ownership and/or control of the factors of production;
2. *social insurance model* (also known as the Bismark model), characterized by compulsory universal coverage generally within the framework of Social Security and financed by employer and individual contributions through nonprofit insurance funds, and public and/or private ownership of factors of production; and
3. *private insurance model*, characterized by employment-based or individual and/or employer contributions and mainly private ownership of the factors of production (Graig, 1999, p.2; OECD, 1987, 1994).

Jessica Adolino and Charles Blake (2001) produced a similar grouping of major policy options. The polar extremes remain the same, with the national health service on one extreme and the market-maximized model on the other. However, their paradigm includes the single-payer model and the mandatory national health insurance model; further dividing the “social insurance model” referred to in Graig’s classification. In the single payer model all citizens are guaranteed access to health care through a single program. The government provides almost all of the funding, but care is administered by private hospitals and physicians. This system is used in Canada, and is funded with general government revenues (Adolino and Blake, 2001, p. 210).

In the mandatory national health insurance model, governments guarantee access to care for all citizens, but with “multiple payers and multiple providers” (Adolino and

Blake, 2001). “Many citizens receive health coverage through private insurance, often tied to their jobs, but government regulations guarantee certain benefits or control costs and fees” (Adolino and Blake, 2001). Governments may also provide health care to the self-employed, unemployed and retirees through various programs.

A final and broader approach to classifying health care systems was created by Odin Anderson, a leading health care policy scholar. Anderson places health care systems on a “health services continuum.” According to Anderson, “The degree to which a state centralized financing and planning and the relative size of its public sector determine its position in the continuum, as does the extent to which it intervenes in the operations of the economy itself” (Anderson, 1989, p. 21).

Once again, the United Kingdom is found at the “market minimized” end, while the U.S. is located at the opposite extreme, the market-maximized pole of the continuum (Graig, 1999). “Anderson’s notion of a continuum underscores the importance of the overall political process and the decision-making roles played by the public and private sectors regarding the development of health care systems” (Graig, 1999). Anderson does not deny government involvement in the U.S., or the incorporation of market systems in the UK, but contends “the U.S. has the lowest share of total health expenditures that are publicly funded, whereas the UK has the highest” (Graig, 1999, p.4; Anderson, 1989).

It has been noted that the continuum is shrinking due to the fact that nations have attempted similar health care reform strategies. “These efforts represent a search for a compromise position that preserves the best elements of existing systems while selectively adapting processes and techniques that have been successful in other health care systems in addressing shared concerns” (Graig, 1999, p. 4; Kirkman-Liff, 1989).

Richard Saltman and Josep Figueras (1998) have referred to this convergence as a “hybrid approach.” It is also known as the *managed, quasi* or *internal market* (Graig, 1999). Rather than viewing the market as a positive or negative force, “the market is viewed as a policy tool to be used by government to enhance the efficiency of the health care sector” (Graig, 1999).

This convergence of the health care continuum can also be linked to the emergence of a global economy and correspondingly, a more interdependent world (Graig, 1999). This has noticeable implications for health care in industrialized countries. “Many nations, for example, are realizing the potential benefits that could be enjoyed from working together on approaches to such shared health-related problems as AIDS, cancer, drug addiction, and aging populations” (Graig, 1999, p. 6; Davis, 1990).

Despite the benefits of convergence, there are limitations, including government structures and institutions and the culture of each nation. As such, it is highly unlikely that the U.S. will ever have a universal health care system, or for the UK to employ a market-maximized model. Although the shrinking continuum/limited convergence theory is useful, for the purpose of this thesis, I will focus on the models outlined by Graig (1999) and Adolino and Blake (2001); specifically the national health service model (UK), and the market-maximized model (U.S.).

The UK Health Care System

The provision of general public health services is where the similarities in U.S. and UK health care policies end. As previously outlined, these two nations are on opposite ends of the health care policy spectrum. The U.S. health care system falls into

the market maximized model while the UK provides a National Health Service which guarantees all citizens access to medical care (Adolino, 2001).

The NHS was created after the end of WWII and was inspired and recommended by the Beveridge Report (Theodoulou, 2002). The Beveridge Report was presented to the British parliament in November 1942 by its author, Sir William Beveridge (British Health Service, 2006). The Beveridge report summarized principles needed to banish poverty and 'want' from Britain. "Beveridge's mantra throughout the report was 'Abolition of want'. The paper proposed a system of social security which would be operated by the state, to be implemented at war's end" (bbc.co.uk, 2006). In the election of 1945, Clement Attlee and the Labour Party defeated Winston Churchill's Conservative Party. Attlee then announced the commitment to develop the Welfare State as outlined in the Beveridge Report. This included the establishment of the NHS in 1948, with free medical treatment for all British citizens. "A national system of benefits was also introduced to provide social security, so that the population would be protected 'from the cradle to the grave'". (www.bbc.co.uk, 2006).

The Department of Health in the UK controls 28 Strategic Health Authorities (SHAs) which oversee all the National Health Service (NHS) operations in a particular area (bbc.uk, 2006). The SHAs supervise:

- Primary Care Trusts (PCTs), which administer primary care and public health.

There are 302 PCTs, which oversee England's 29,000 General Practitioners and 18,000 NHS dentists. In addition, they oversee such matters as primary and secondary prevention, vaccination administration and control of epidemics.

- NHS Hospital Trusts. These 290 organizations administer hospitals, treatment centers and specialist care in the about 1,600 NHS hospitals (many trusts maintain between 2 and 8 different hospital sites).
- Ambulance Trusts
- Care Trusts
- Mental Health Trusts (bbc.co.uk, 2006).

In addition, several SHAs provide health services to the entire United Kingdom. These services include NHS Blood and Transplants, as well as the NHS Direct and National Institute for Health and Clinical Excellence (NICE) (bbc.co.uk, 2006).

Ninety percent of NHS expenses are absorbed by the government and paid through general government revenues (Adolino and Blake, 2001). The government pays hospitals, doctors, nurses and other medical staff directly to provide care. Most of the hospitals are publicly owned and managed and receive their budgets from the NHS based on the health trends in their area.

While costs are a substantial issue for the NHS, it has managed to contain health care costs relatively well. In fact, the total health expenditure in the UK was about 7% of the GDP from 1990-1998 versus 14% of the GDP in the United States over the same time period (Theodoulou, 2002).

Although Britain spends far less per capita on medical care than does the United States, it has 13 percent more acute care hospital beds per capita, 64 percent as many doctors, 55 percent as many nurses, 25 percent more admissions to acute care hospitals, and similar length hospital stays.

Crude indicators of health status put Britain abreast or slightly ahead of

the United States. Life expectancy at birth was higher and infant mortality was lower in Great Britain than in the United States in the year 2000 (Aaron et al, 2005; Arias, 2000; Office for National Statistics (UK), 2002; T.J. Mathews et al, 2000).

The UK is able to keep costs low through a variety of methods, notably the use of general practitioners (GPs) as gatekeepers. The GP takes care of basic health care concerns and refers patients to specialists if necessary. This serves a gate-keeping function by limiting access to more expensive, specialized care. In addition, the UK practices other cost containment measures including: requiring co-payments at the time of service, paying doctors on a fee-for-service basis, and through limits on technology acquisition. The central problem cited in the UK health care system is the presence of waiting lists or other forms of rationed care which occur when the demand for certain services exceeds the supply. In June 1990, former British Prime Minister Margaret Thatcher set maximum waiting periods for various procedures. The NHS was also given large budgetary increases during the 1990s to help remedy this problem (Theodoulou, 2002).

Private healthcare exists in the UK, but to a much lesser extent than in the USA. Since the National Health Service provides comprehensive health service, private health insurance only provides a supplemental level of health care. "In the UK Health insurance only provides coverage for curable, short-term health problems. It is designed to enable policyholders to jump the NHS queues to see consultants, be diagnosed, receive surgery or be treated. It does not cover medical care for emergencies or accidents and nor does it provide preventative medical treatment" (bbc.co.uk, 2006). Thus, only 12% of Britons

have private health insurance, compared to 85% of Americans, and the majority of those (9% of Britons) have their private insurance paid by their employer (bbc.co.uk, 2006).

This type of insurance is treated as a benefit and is subject to income tax in the UK.

UK Health Care Reforms

The above description of the National Health Service includes many of the reforms introduced by Prime Minister Margaret Thatcher in 1989. Thatcher's goal was to incorporate market mechanisms into the NHS, and to change the dynamics of accountability within the NHS's administration. Prior to 1989, "doctors were the dominant actors and managers played supporting roles" (Giaimo, 2002, p. 31). In addition, administrative arrangements of the NHS prevented the state from sufficiently governing the health care sector, and "medical associations failed to police their own members" (Giaimo, 2002, p. 31).

In the end, the thorn of political accountability provided the most compelling reason for Thatcher to seek changes in NHS governance. Because statism accorded the central government the primary voice in decisions about provision and financing, voters and Parliament held it responsible for NHS performance, good or bad. Furthermore, they also held the government of the day responsible for safeguarding universal access to care. Voters could ostensibly use the ballot box to call the government to account for its stewardship for the NHS, though this was a blunt instrument wielded infrequently (Giaimo, 2002, p. 41; Harrison, 1988, p. 92-97).

Thatcher's review of the NHS resulted in the January 1989 publication of the white paper *Working for Patients*, which outlined substantial changes in NHS governance. This overhaul was spurred by the public debates over the NHS in 1987, and the "widespread media coverage of burgeoning waiting lists, ward closures, and staff layoffs (Giaimo, 2002, p. 43-47).

Despite Thatcher's intent to radically alter the NHS, the reforms fell short of her sweeping vision. The NHS did receive an internal market, "but one that was heavily managed from the center" (Giaimo, 2002). For example, district authorities may now purchase care from an array of public and private providers, which is intended to promote competition and increase care standards. The government also introduced co-payments for certain services and some prescription drugs, although certain groups such as pregnant women, children, those in poverty and the elderly, are exempt from paying. The revenues from these co-payments cover approximately 5% of NHS services (Adolino and Blake, 2001).

One reason Thatcher's proposed reforms were stunted, was due to her ousting in 1990, and the subsequent installment of John Major as Prime Minister. "The Major government realized it could not run the NHS without doctors or with a profession whose morale was completely shattered" (Giaimo, 2002, p. 71). Major pursued a "steady state" policy which entailed renewed and conciliatory talks with the BMA, and concede some autonomy to the medical profession (Giaimo, 2002). Under the Major government, Patient Charters were also introduced in 1992 in order to "improve service and guarantee high levels of patient care" (Theodoulou, 2002). Institutional and political factors also slowed Thatcher's reforms. Susan Giaimo (2002) summarizes:

In sum, one cannot make sense of this seemingly contradictory mixture of “market and state” unless one looks at both the sectoral and political arenas and the interactions between them. Britain’s political institutions, which centralize power in the cabinet, promote party discipline, and inflate electoral majorities, facilitated Thatcher’s aggressive pursuit of her radical market agenda and permitted her to enact her reforms with relative ease... Thatcher discovered that there were limits to how far she could push her neoliberal vision in the health care system. Both she and Major decided that unleashing a laissez-faire market into a health service built upon the principles of universalism, solidarity, and public financing would have entailed prohibitive political costs, and therefore they sought to mold and tame the market with state power (Giaimo, 2002, p. 78-79).

In addition, “It is virtually impossible to know whether Thatcher’s claim that market pressures could generate these outcomes was validated because the Major government gave the NHS its largest budgetary increase in over a decade during 1991-1993” (Adolino and Blake, 2001, p. 233).

The Labour government of Tony Blair, which was elected in 1997, issued the white paper *The New NHS: Modern, Dependable*. This served as the crux of the 1999 Health Care Act. The government introduced several initiatives such as the Health Improvement Programs, Health Action Zones, and Healthy Living Centers. “Basically this shifts the emphasis from health care to good health. It is hoped to regenerate communities and raise the standards of health” (Theodoulou, 2002, p. 154). Blair’s vision also entailed: collaboration rather than competition between purchasers and

providers; abolished GP fundholding and replaced them with Primary Care Groups (general practitioners in practice or PCGs), in order to reduce the fragmentations that fundholders had introduced; the reforms also restored democratic principles to Trusts, including renewed public accountability and the mandatory publishing of annual performance reports (Giaimo, 2002, p. 80-81).

The future of the NHS is not as restricted by cost as other nations will be. "In contrast to most industrialized nations, the major British health care reform issue has not been cost control" (Adolino and Blake, 2001, p. 232). This is evident in Prime Minister Blair's long-term vision for the NHS, unveiled in 2000, which focused on underfunding and waiting lists. "Blair's pledge to devote 20 billion pounds (\$31 million) to the NHS over four years, an increase of 6.1 percent, will bring the British health care spending closer to the European Union average. Much of it will go to additional doctors, nurses and hospitals" (Giaimo, 2002, p. 82; UK Department of Health, 2000). The Labour party also wishes to ensure that quality care is available to anyone with a clinical need, rather than where someone lives. This refers to the regional disparities which Labour hopes to solve with performance targets (Theodoulou, 2002, p. 156).

The U.S. Health Care System

The United States has a market-maximized model of health care policy. There is no guarantee that access to medical care will be available to all citizens, although the law requires that all hospitals must provide emergency treatment. Most people in the U.S. are covered by private insurance providers, many of which are offered by employers to their employees. Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs), and Independent Practice Associations (IPAs) are all examples of

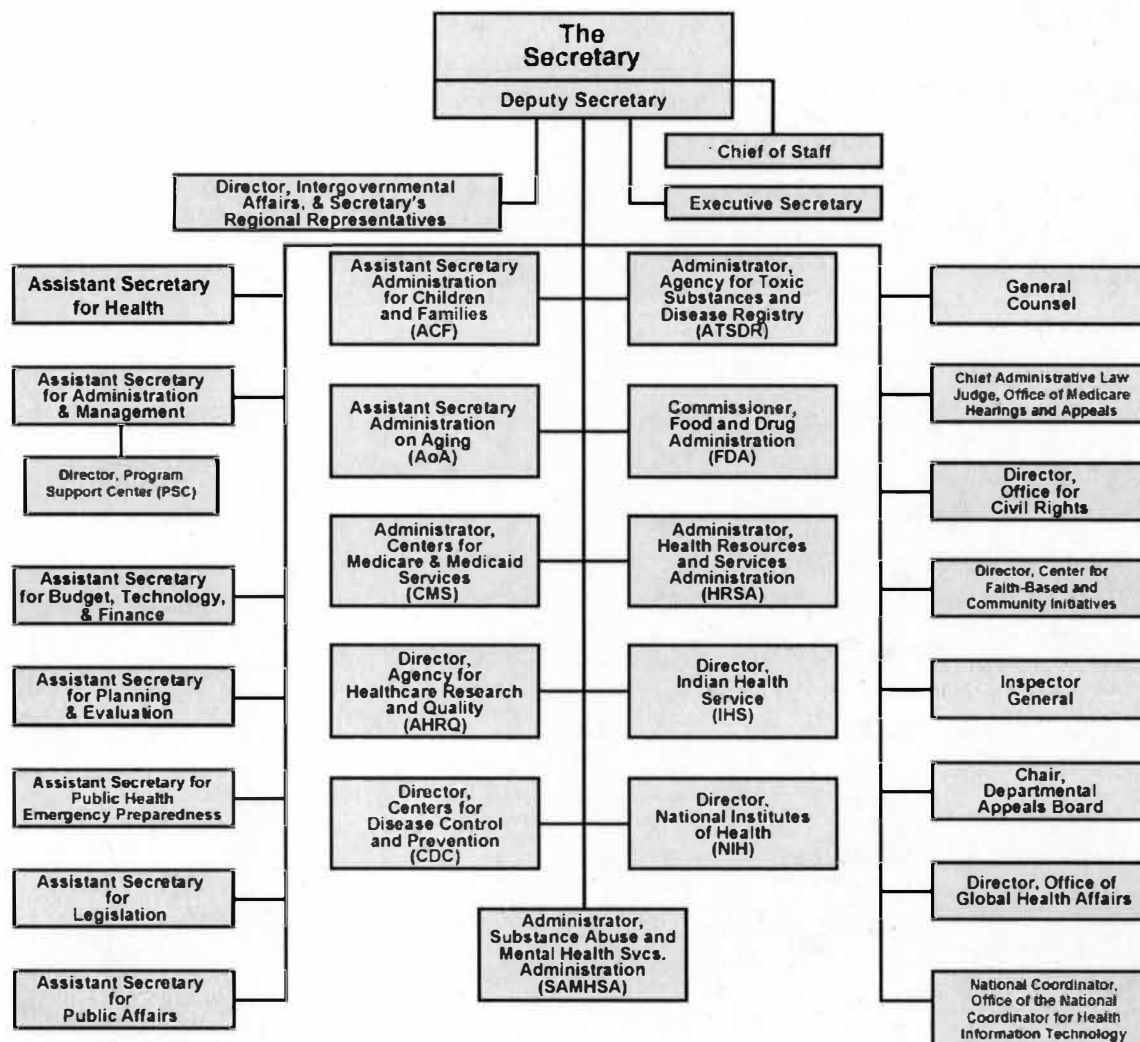
employment-based health insurance programs. The government regulates the private insurers, but this regulation is not “at the level found in the mandatory national health insurance model” (Adolino and Blake, 2001).

The Cabinet department of Health and Human Services (HHS) is one of the most active departments in the executive branch (Siplon, 2002, p. 9). The HHS includes the Public Health Service, which is led by the Surgeon General of the United States; the Public Health Service contains the Center for Disease Control (CDC), which first tracked the emerging HIV/AIDS epidemic. The National Institute of Health (NIH) which studies major diseases through public research funds, and the FDA, which regulates food and drug products are also housed within the HHS (Siplon 2002, p.9). Figure 1 (pg. 33) illustrates the organizational structure of the HHS, as well as the department’s complexity.

The federal government provides health care to the elderly and those in poverty through Medicare and Medicaid programs. Medicare provides access to those 64 years old and over, while Medicaid entitles various groups, such as the disabled and those receiving social assistance to medical benefits. However, there is a significant portion of the U.S. population which is not covered by any health insurance program. It is estimated that in the 1990s one in seven people, or 40 million Americans, did not have health insurance (Thecdoulou, 2002; Adolino and Blake, 2001). Today, that figure has grown to 15% of all American citizens, or 45 million people (Aaron et al, 2005). Most hospitals in the U.S. are privately owned and operate on a non-profit or for-profit basis.

Figure 1: The Structure of the U.S. Department of Health and Human Services

(HHS.gov)



Source: U.S. Department of Health and Human Services, (www.hhs.gov)

The problem of access lies primarily with incomplete coverage of private and public insurance, making health care unaffordable for those without insurance. To be sure, most Americans were covered by group plans

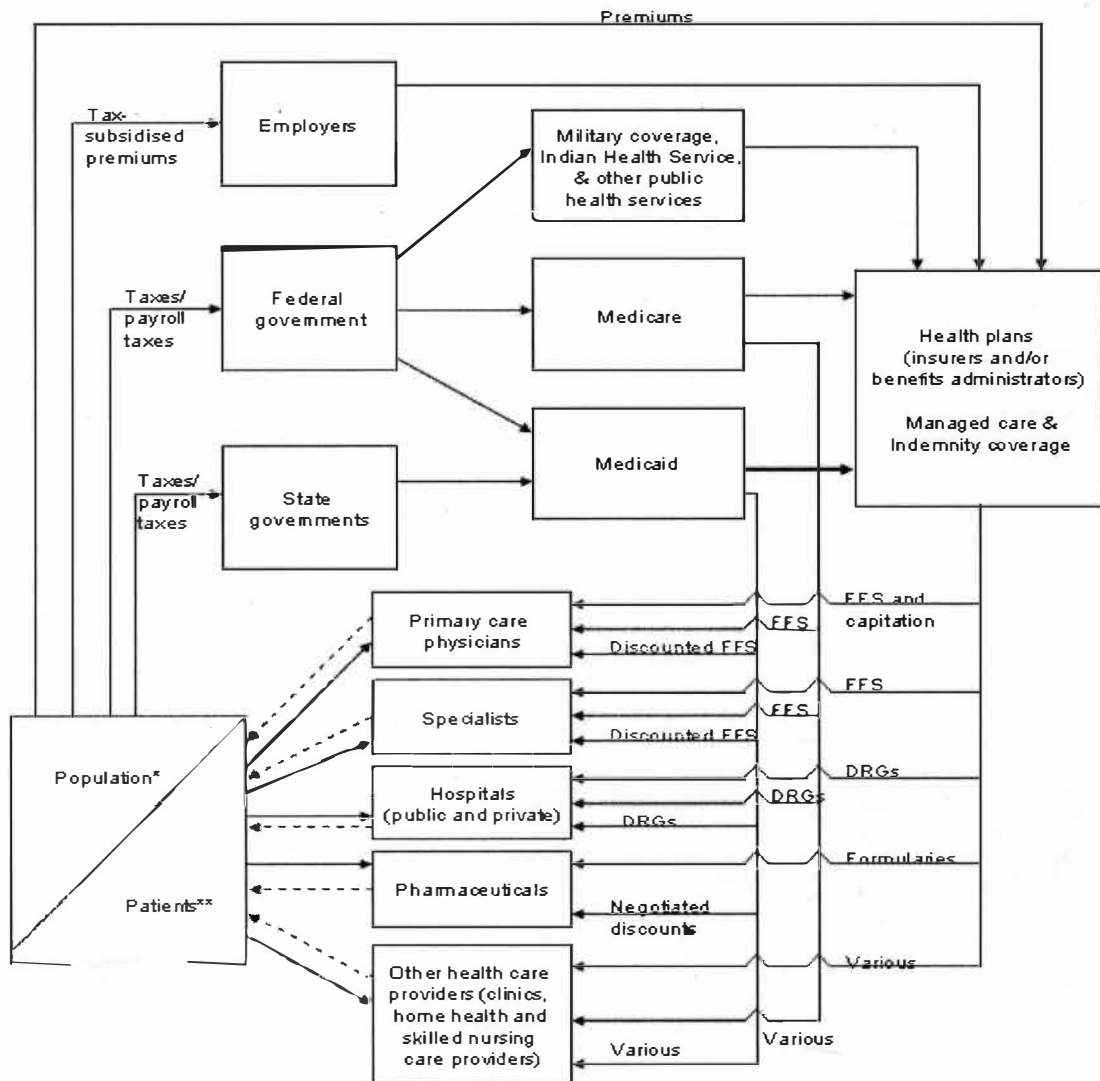
offered by their employer, while the elderly and poor... had coverage under Medicare and Medicaid, respectively. Employers were free to not offer insurance, and many of them did not, particularly for contingent employment or in sectors where unions were weak. Workers in these types of jobs often had incomes too high to qualify for Medicaid, yet too low to afford private insurance (Giaimo, 2002, p.161).

The complexity of financing health care in the United States is illustrated in Figure 2 (page 35). This figure shows the flow of funds from the general population to the government through taxes, employers, and/or general premiums given directly to health plans, and the way these funds are distributed to a variety of health care providers and services.

The greatest problem with the market-maximized model is the number of people who do not have access to affordable health care. Health services in the U.S. are arguably rationed by the client's ability to pay, with those in the working and lower classes having less access than the upper class (Adolino and Blake, 2001). The U.S. health care system is also plagued by rising health care costs, with approximately 14-16% of GDP being spent on health care expenditures (Theodoulou, 2002). In fact, "no other nation spends nearly as much on health care as does the United States," (Aaron et al, 2005, p. 6).

Figure 2

Health care financing in the United States, 2003



NOTE: FFS is fee-for-service payment DRGs are case-based payments to hospitals based on a diagnosis-related group system.

*Health care for the 14% of the population lacking health insurance coverage is financed by publicly subsidised charity care and patients' out-of-pocket payments to health care providers.

**Patient cost-sharing arrangements vary widely by type of coverage. Indemnity coverage generally includes deductibles and co-insurance. Managed care plans often require co-payments for certain services.

Source: OECD Secretariat, 2003.

NOTE: Solid lines represent direct relationships; Dashed lines indicate indirect relationships.

Per capita health care spending in the United States, at \$5,267 in 2002, was more than twice the \$2,049 average of other members of the Organization for Economic Development (OECD) and more than half again as great as spending in the second highest spending nation – Switzerland (\$3,446). These differentials are attributable to several causes. First, U.S. physicians receive particularly generous remuneration. Second, rich nations may spend a larger share of their income on health care than do poorer nations, and the U.S. is richer than most other OECD nations. Third, the United States tends to have more medical equipment and higher rates of surgery than do most other nations (Aaron et al, 2005, p. 7; OECD Data, 2004; Gerdtham and Jonsson, 2004).

In addition, and due to the fragmented, decentralized nature of the U.S. health care system, there is a large administrative effort which must be sustained, resulting in higher costs. The rapid advancement in technology has been blamed for unnecessary costs as well, since hospitals try to acquire the most up-to-date equipment for use on a very small portion of the population. Another problem with the market-maximized system is that it may put profits above health care. For example, most HMOs pay doctors on a capitation basis, which means the more patients they see, the more they will earn. In a fee-for-service system, doctors are paid for each service they provide regardless of how many patients are treated.

U.S. Health Care Reforms

The U.S. has been attempting to reform health care policy for decades. The 20th century is riddled with numerous, but failed, initiatives to enact national insurance, universal coverage and/or some combination of the two. "...Private actors joined forces with partisan allies in Congress to block these initiatives. Public policies also combined with private actors to institutionalize the private, fringe-benefit system" (Giaimo, 2002, p. 149). While some reforms have been initiated, such as the Medicare and Medicaid programs, the vast majority of reforms proposed for the U.S. health care system have failed, resulting in 45 million Americans without health care coverage, with the most spent on health care in the world (as a percentage of GDP) (Theodoulou, 2002; Adolino and Blake, 2001; Giaimo, 2002).

Franklin Roosevelt considered national health insurance as part of the Social Security proposals. However, with AMA opposition, and the emergence of an alliance between southern Democrats and northern Republicans in the 1938 mid-term elections, Roosevelt was forced to table the issue for the remainder of his tenure (Starr, 1982; Giaimo, 2002). Harry Truman was also a strong advocate of national insurance throughout his tenure in office. Truman faced effective opposition from employers, the conservative alliance, and the AMA, which linked national insurance to "socialized medicine" and the broader crusade against communism (Starr, 1982; Giaimo, 2002).

After these repeated defeats in Congress, organized labor turned to the labor market directly. This was facilitated by the wage and price controls of WWII, when companies offered benefits in order to attract and retain labor. The Supreme Court's 1948 *Inland Steel* decision gave unions the right "to include health insurance in collective

bargaining. Unions responded by making health insurance a priority in collective bargaining, and workplace coverage expanded in the postwar period. Government tax policies also encouraged the development of private fringe benefits by granting employers a tax exemption on their insurance contributions” (Stevens, 1988; Giaimo, 2002).

The fight for universal coverage was scaled back to a demand for public insurance for those with “obvious need, commanded public sympathy, and were deserving of government help” (Giaimo, 2002, p. 151). This included senior citizens and the poorest members of society such as the disabled and children of single, non-working women. The 1964 elections resulted in large Democratic majorities in both Houses, which in turn yielded Lyndon Johnson’s New Society initiatives including the Medicare and Medicaid insurance programs of 1965 (Adolino and Blake, 2001). However, this mix of private and public insurance left many without insurance, particularly non-union workers, and the working poor.

The 1970s saw another push for national health insurance initiatives, which followed the fate of their predecessors by failing to be enacted. In 1970, Senator Edward Kennedy “proposed a single-payer model of compulsory national insurance” (Giaimo, 2002), much like the system that Canada has today. Nixon proposed employer mandates and coverage for the working poor. The Nixon administration also favored prepaid health care services dubbed “health maintenance organizations” (HMOs) by Paul Elwood, a Minneapolis physician (Graig, 1999). “HMO enrollees receive comprehensive benefits from a defined network of providers... based on fixed payments in advance regardless of how much health care the individual consumes” (Graig, 1999, p. 23).

The Health Maintenance Organization Act (1973) featured subsidies to promote HMO growth, and set standards of coverage for HMOs (Graig, 1999). In 1974, Nixon revised his original proposal to increase its scope of coverage, but it too failed. In 1978 Senator Kennedy again proposed national health insurance. President Jimmy Carter countered Kennedy's proposal with one similar to President Nixon's, but in a climate of staggering economic concerns, neither plan could reach a consensus in Congress (Starr, 1988; Giaimo, 2002).

President Ronald Reagan's health care policy goals included proposals to reduce federal funding to health programs, putting a cap on Medicaid funding, and giving more authority to the states; none of which were fully realized (Patel et al., 1999). The Reagan administration was particularly interested in granting states more discretion and control over health care "when such discretion promised cost reductions" (Patel et al., 1999, p. 68). Budget cuts were made to both Medicare and Medicaid, and new federal grants for HMO startups were eliminated during Reagan's tenure (Patel et al., 1999, p. 175).

In 1993 the Clinton administration pledged to create a national health care system to remedy the problems of unequal access and burgeoning costs. Although Clinton was elected by only 43% of the popular vote among three candidates, his "bold proposals initially met with public enthusiasm and a willingness among many members of Congress to work with the President. President Clinton appointed a special task force to develop a comprehensive reform proposal, which was led by his wife, Hillary Clinton.

However, once policy formulation began in earnest, the Democratic majority in Congress was visibly divided on which model to adopt, and most Republican legislators bitterly opposed the managed competition

plan favored by the presidency. In addition, the Health Insurance Association of America launched a biting media campaign aimed at reducing popular support for the President's plan by asserting that the proposal would reduce patients' choice, increase their costs, and decrease the quality of services provided (Adolino and Blake, 2001, p. 220)

Although the Health Insurance Association of American had engaged in a very effective media campaign, other interests groups – notably the American Association of Retired Persons (AARP) and the American Medical Association – sponsored ads that supported the key elements of the Clinton plan, without specifically stating the name of the plan (Giaimo, 2002, p. 175). This was a problem due to the fact that six major health reform bills were proposed during the 1993-1995 session, with the Clinton's Health Security Act being introduced late in the session (Adolino and Blake, 2001). These initiatives traversed the policy and political spectrum. The Health Security Act proposed “compulsory, universal national health insurance through an employer mandate. The government would have also provided subsidies for insurance to small firms and individuals not attached to the labor market” (Giaimo, 2001, p. 163).

The Clinton example highlights the difficulty of a president to initiate major legislation in the U.S. political system. The failure of Health Security to even reach a floor vote came not at a time of divided government, but during a session in which both Houses were under slim, but nonetheless Democratic majorities (Giaimo, 2001; Adolino and Blake, 2001). “In general, American political institutions fragment authority and make radical policy change difficult and rare (Giaimo, 2001, p. 169; Weir, Orloff and

Skocpol, 1988, p. 21-24). Jessica Adolino and Charles Blake summarize the dynamics behind this experience:

The health care reform experience under the Clinton administration demonstrates a series of obstacles that make major expansion of government activity difficult in this sector. Many citizens are skeptical of government intervention. Interest groups are able to mount private and public lobbying campaigns on behalf of their preferred policy positions so that reformers find it difficult to see their vision rise to the top of the systematic agenda unchallenged. The federal system dictates that policy can be made (and blocked) at multiple levels of government. The presidential system of executive-legislative relations permits not only the possibility of divided government but also the daily reality of a decentralized legislative process in which multiple poles of power exist in both houses of Congress... This is a telling reminder about the ability of the president to generate major legislation in the U.S. political system: It depends largely on the president's success at persuading both the public and individual legislators to support a presidential initiative (Adolino and Blake, 2001, p. 221).

What has emerged since the failure of Health Security is a rise in employer-led market reform that "relies on price competition among managed-care organizations" (Giaimo, 2002, p. 185). In addition to the problems of access, the U.S. is faced with the challenges of rapidly rising health care costs, an aging population, and a sluggish economy. It is undoubted that health care will be a major issue in future elections, but

the structure of the U.S. political system will prove a formidable opponent to any major legislation.

CHAPTER VI

AIDS POLICY OVERVIEW

The Human Immunodeficiency Virus (HIV) is a retrovirus that infects cells of the human immune system. It is widely accepted that infection with HIV causes Acquired Immunodeficiency Syndrome (AIDS), a disease characterized by the destruction of the immune system (CDC.gov, avert.org). However, there are a few members of the scientific community and several groups that maintain that HIV has never been proven to cause AIDS. This is known as the denialist perspective. These people believe that since AIDS is a syndrome and not a singular disease that other factors such as poverty or drug use cause AIDS. The scientist Dr. Peter Duesberg is the main proponent of this view, arguing that poverty is to blame for AIDS, not HIV (Siplon, 2002, p.14). Both far-left organizations (ACT UP San Francisco) and far-right groups (Heritage Fund) in the USA have taken this view, and in 2000, South African President Thabo Mbeki reignited this debate by openly questioning the link between HIV and AIDS (Siplon, 2002). For the purposes of this paper, the link between HIV and AIDS will be accepted.

HIV is not transmitted through casual contact. The three most common modes of transmission are sexual contact, sharing needles and syringes, and mother-to-child (cdc.gov). A fourth route of transmission is through the transfusion of blood, which due to a variety of policy initiatives and regulations on blood supplies in the 1990s is no longer common in advanced, industrialized nations (avert.org).

There is no cure for HIV/AIDS; thus, HIV/AIDS prevention is based on behavior modification, or urging people to avoid behaviors that cause HIV to be transmitted (Siplon, 2002). There are two major strains of behavior modification; abstinence and

harm reduction. Abstinence is discontinuing at-risk behavior entirely. Proponents believe that if the sexual or drug using behavior is completely avoided, transmission is impossible. Harm, or risk reduction assumes that people may continue behaviors that put them at risk for a number of reasons. Thus, harm reduction adherents find ways to “encourage people to conduct these behaviors in a way that minimizes the risks that come with them” (Siplon, 2002, p. 68). The struggle between these two strategies is apparent through much of the policy process in both the USA and the UK.

A comprehensive outline of HIV/AIDS and corresponding public policies and initiatives is beyond the scope of this paper; however, a brief synopsis of important developments is valuable in establishing the progression of the disease. Symptoms of what would later be termed AIDS were present in the USA as early as 1979, and the first case in the UK appeared in 1981 (Small, 1993, p.90). On June 5, 1981, the U.S. CDC gave its first warning about a rare disease that would later be known as AIDS in a brief report. In 1983 former President Ronald Reagan’s Secretary of HHS, Margaret Heckler announced that the probable cause of AIDS had been found, and by 1984, scientists had found the viral agent that causes AIDS, which in 1986 would be termed HIV (CDC.gov; Siplon, 2002, p. 13). In 1985, there was a rapid rise in media attention both in the USA and the UK; possibly due to the fact that a well known actor, Rock Hudson, revealed that he had contracted AIDS (Siplon, 2002). In 1987, AZT, the first antiviral agent for the treatment of AIDS was approved by the U.S. FDA (Siplon, 2002).

During this period of intense scientific research there was an equally intense health policy debate about how to prevent the spread of HIV/AIDS. Private organizations began surfacing in both countries in 1982 with groups such as People with

AIDS (PWA) in San Francisco, and the Terrence Higgins Trust (THT) in Britain (Small 1993). These groups began developing their own educational materials, hotlines and seminars on the emerging crisis, as well as alerting at-risk community members of possible infections. "People infected with HIV during early years were educated, affluent, already had resources of money, time and skills that often are less available when disease occurs among people who are very poor" (Siplon 2002, p. 5). African American groups first began speaking out about the transmission of HIV due to drug use, and focused on AIDS policy regarding needle exchange programs. In the mid-1990s African American religious groups began to contribute to the policy process as well (Siplon 2002, p. 7-8).

In contrast, HIV/AIDS was neglected in its early years by both governments as described by Neil Small, "The denial and hostility evident in Britain on the part of the government was also present in the USA" (Small, 1993, p. 80). One example of this hostility occurred in 1985 when then British Secretary of State Norman Fowler refused to compensate 1,200 hemophiliacs who had received infected blood in state medical facilities; in fact, they were denied compensation until an announcement in 1987 by then Minister of Health Tony Newton (Small, 1993). In 1987, U.S. Senator Jesse Helms proposed Amendment 956 which would have prohibited the CDC from using any government funds to "provide AIDS education, information, or prevention materials and activities that promote, encourage or condone sexual activity outside a sexually monogamous marriage (including homosexual activities) or the use of intravenous drugs" (Siplon, 2002, p. 67). This amendment was finally modified only to prohibit funds that would seem to be promoting homosexuality (Siplon, 2002). The government's role in the

UK was equally obstructive. For example, in the early 1980s UK Customs confiscated books and magazines from the U.S., many of which contained up to date information on HIV/AIDS under the pretense that the materials were pornographic in nature (Small, 1993, p. 91).

Media attention of AIDS spiked in 1985-86, resulting in pressure on the government's of both nations. The U.S. Congress felt this urgency from community-based organizations and attempted to increase spending in 1985; the Reagan administration resisted (Small, 1993, p. 92). Both nations began allocating significant amounts of money towards HIV/AIDS research and education in 1986-87. In the UK, the Health Education Council's (HEC) first AIDS leaflet was developed, 6 million pounds (approximately \$11.7 million) were granted to AIDS related work, and 5 million pounds (approximately \$9.8 million) was given to a drugs and AIDS campaign, which was to be aimed at drug users and potential users (Small, 1993, pp. 93-96). In the U.S., millions of dollars provided by private donors, public groups, and the government were spent on HIV/AIDS research, and in 1988 the first 6-page pamphlets on AIDS were mailed out to 107 million American homes (Siplon, 2002, p.70).

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (1990) was the first and most prevailing piece of national AIDS legislation in the United States (Siplon, 2002). In 1990, the Act was passed 95 to 4 in the Senate and 408 to 14 in the House (Siplon, 2002, pp. 93-94). The CARE Act contained four titles: I. Disaster relief to eligible metropolitan areas (EMAs); II. Grants to all 50 states; III. Special project grants for early intervention; IV. Special services for women, infants and children

(Siplon, 2002). The Health and Services Administration (HRSA) is the government agency responsible for carrying out the CARE Act after Congress has allocated funding.

The HRSA works mainly with the EMAs. To qualify as an EMA, a metropolitan area had to have a minimum cumulative caseload of 2,000 infected persons or at least 0.0025% of its population as of June, 3 1990 (Siplon, 2002, p. 96). Each EMA is then responsible for appointing an HIV Health Services Planning Council (HHSPC), which can be a new group or an existing organization (see Figure 3, p.49). "The HHSPC is in charge of who and what community groups receive funding and are responsible for deciding what is the best method to deliver services. HHSPCs must have representation from 11 different community groups including service professionals, local leaders, and affected communities" (Siplon 2002, p.96). The first fiscal year of the CARE act (1991) there were 16 qualifying EMAs, and by 1999 that number rose to 51 (Siplon, 2002, pp. 96-7). Funding for Title I also increased dramatically; in 1991 \$86 million was allocated to EMAs and by 1999 that number had grown to \$485 million (Siplon, 2002, p.97). New York City and San Francisco received and continue to receive the largest amounts of Title I funding (Siplon 2002, p.96).

Under Title II funding each state receives \$100,000, and additional funding is then based on cumulative caseloads and by the average per capita income. Each state must establish an HIV care consortia. In addition, Title II funding may be used to assist home and community based care, but not patient services. Finally, 15% of Title II funding must go to infants, children, women and families. Title III funding is sent directly to individual programs from the public and private non-profit

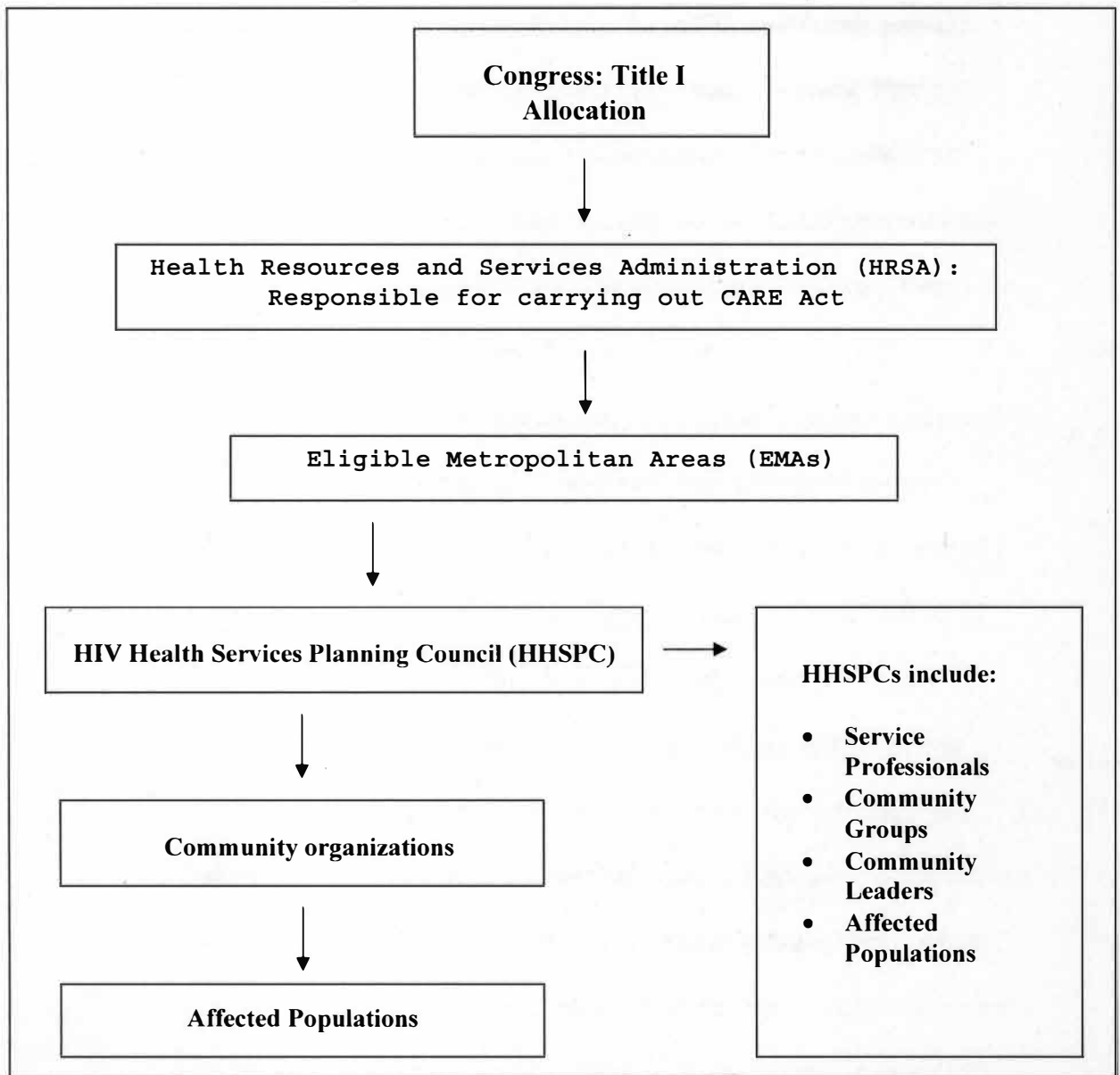
sector organizations already dealing with at-risk populations. Title IV is designed to be family-centered, providing funds to community based services for children, teenagers and women with HIV. Title IV was not funded at all during the fiscal years 1991-1993, and has since 'faired poorly in the allotment of money' (Siplon 2002, p.97).

The most important aspect of the CARE act was its emphasis on local control, local priorities and state and community based programs. Communities could prioritize efforts according to the specific needs of their affected populations. The major problem with this type of funding is that populations which are able to organize and have more resources with which to lobby for their cause, i.e. homosexual males, have an advantage over populations which are fragmented and/or have less resources to spend on lobbying such as minorities, single mothers and those in poverty (Siplon, 1999; Rundall et al, 1999; Gilbert, 2003).

During the late 1980s and throughout the 1990s, the British government allocated funds to various public service advertising campaigns, 15 needle exchange programs, and some targeted campaigns including drug users, young heterosexuals and in 1989 homosexual males (Small, 1993, pp. 93-9).

Early campaigns attempted to alert the entire country about the effects of HIV/AIDS, which did not overcome "the initial belief that AIDS was a gay disease" (Small, 1993). One of the largest problems with these campaigns was that they did not work with community organizations, volunteer groups, or local health professionals. In addition, "the financial orthodoxy of the NHS does not aid in an imaginative response to the problems generated by HIV/AIDS" (Small, 1993, p. 76).

Figure 3



Source: Compiled by the author based on information in *AIDS and the Policy Struggle in the United States*, (Siplon, 2002).

Thus, in 2000, ten years after the Ryan White CARE Act was legislated in the USA, the Sexual Health and HIV Strategy and Action Plan (SHAP) in the UK was introduced. This was the first national sexual health and HIV strategy in the UK and was drafted with the assistance of professionals in the health service and policy fields, service

users and target groups (SHAP, 2001). The Strategy also emphasized the crucial role of voluntary organizations, particularly in the HIV field. The NHS had already provided citizens of the UK with information about HIV risks, open access to Genito-Urinary Medicine (GUM) clinics, needle exchanges, and a variety of free contraceptives, yet recognized that services needed to be modernized (SHAP, 2001). The UK set out a ten-year plan to achieve its goals with a dedication of 47.5 million pounds to be allocated for the first two years of the program. Strategy highlights include:

Providing clear information so that people can take informed decisions about preventing HIV; ensuring there is a sound evidence base for effective local HIV prevention; setting a target to reduce the number of newly acquired HIV infections; developing managed networks for HIV and sexual health services, with a broader role for those working in primary care settings and with providers collaborating to plan services jointly so that they deliver a more comprehensive service to patients; evaluating the benefits of more integrated sexual health services, including pilots of one-stop clinics, primary care youth services and primary care teams with a special interest in sexual health; improving access for urgent appointments; ensuring a range of contraceptive services are provided for those that need them; increasing the offer of testing for HIV and setting a target to reduce the number of undiagnosed infections, thereby ensuring earlier access to treatment for those infected and limiting further transmission of the virus; setting standards for the treatment of STIs and for the treatment, support and social care of people living with HIV;

setting priorities for future research to improve the evidence base of good practice in sexual health and HIV; and addressing the training and development needs of the workforce across the whole range of sexual health and HIV services (SHAP, 2001, pp. 4-6).

The governments in both the US and UK have admitted that there is a relationship between sexual ill health and poverty (Siplon, 2002; SHAP, 2001), and have recently designed legislation in an attempt to remedy the inequality of education and health care access among lower socio-economic groups. It is beyond the scope of this paper to analyze each individual program and whether progress has been made in improving access to governmental resources. However, it is possible to demonstrate that certain groups, which are emerging as those most affected by HIV, have limited access to resources for a variety of reasons, and that certain programs may be more effective than others in providing information, preventative measures, and care to those already infected.

HIV/AIDS Drugs

HIV/AIDS drug policy has also been a source of heated debate and protest. In the U.S., developing new and effective drugs at an affordable price has been a top priority of community groups. The government has also been interested in keeping costs down and providing access to those who need these medicines. However, pharmaceutical companies in the U.S. have their own interests, and in the early years of the epidemic the struggle over costs and access to these medicines highlighted the competing interests found within the American health care system.

Pneumocystis pneumonia (PCP) was the leading killer of HIV patients in the U.S. in the beginning of the epidemic. PCP could be treated with a drug named pentamidine, which was found to be very effective. Prior to the epidemic, pentamidine was imported from England by the CDC and sent for free to doctors who requested it, due to the fact that it was so rarely used, and could be imported at such a low cost. In 1983, the CDC received more than 2,000 requests for pentamidine from community doctors, causing the CDC to search for a U.S. company to supply it (Siplon 2002, p.26-27). A company called Lymphomed agreed to begin producing pentamidine.

The Lymphomed pentamidine was approved in injectable form by the FDA in 1984, but often the injections did not help patients with PCP because it did not immediately enter the lungs. Community doctors in affected areas recognized this problem and began treating their patients with aerolized pentamidine. The aerolized pentamidine could then be taken much like an inhaler, providing treatment directly to the lungs. While this breakthrough was a victory for doctors and patients, it was limited in its scope because the FDA had not recognized or recommended the use of aerolized pentamidine. Thus, “patients who were well connected and informed (white, gay men in urban areas) had access to a life-saving therapy that others (people of color, rural patients) did not enjoy” (Siplon 2002, p.28).

New York City-based activist Michael Callen decided to launch the crusade for aerolized pentamidine when he discovered that “poster boy” hemophiliac Ryan White’s own physician did not know about the treatment. In May 1987, Callen went to the head of the National Institute for Allergies and Infectious Diseases (NIAID), Anthony Fauci, and asked

him to release guidelines instructing physicians with patients at high risk for PCP to treat it preventively with aerolized pentamidine. Fauci refused, claiming he did not have sufficient evidence on the effectiveness of such treatment to support the issuance of guidelines – in spite of the fact that less than three months earlier, a subcommittee within NIAID had recommended that trials of aerolized pentamidine be given the highest priority. Disgusted activists and community doctors had enough – rather than leaving it to the government or the private sector to study the effects of aerolized pentamidine, they decided to study the effects themselves in a community based trial. Two trials were independently conducted: the San Francisco County Community Consortium, and in NYC the Community Research Initiative. NIAID would not fund either trial... In both cases, the largest sponsor was the pharmaceutical company Lymphomed, which was racing to get FDA approval for the aerolized version (Siplon 2002, p.29).

Congress grilled NIAID head Anthony Fauci as to why aerolized pentamidine studies had no patients enrolled and why the National Institutes of Health (NIH) had not taken the lead in testing aerolizable pentamidine (Siplon 2002, p.29-30). Fauci defended the agency's actions, claiming that the agency was too short-staffed to create a position to oversee an aerolized pentamidine project. Representative Nancy Pelosi (D-Calif) argued with Fauci stating that "it would now be impossible to do the research precisely because no one would be crazy enough to sit around waiting for a trial when they already knew that aerolized pentamidine worked" (Siplon 2002, p.30).

Costs were another problem that Congress and community activists had questioned. “In October 1984, Lymphomed provided a one month supply (300mg vial) of pentamidine for \$25, by August 1987, the same vial cost \$99.45; a fourfold increase in three years” (Siplon 2002, p.30). In response, the People with Aids (PWA) Health Group NYC announced in September 1989 that it would begin importing pentamidine from England since it could be bought at a fraction of the U.S. price (Siplon 2002, p.30). This marked the first organized effort by a buyer’s club to import an approved drug due to cost.

The U.S. controversy over aerolized pentamidine was not carried over into England. One reason was that the epidemic was not as advanced in the UK, and doctors had the advantage of knowing that aerolized pentamidine was effective against PCP due to the U.S. community doctors and activists, and were able to treat emerging patients with the drug (Small, 1993). Another factor was that pentamidine, as already presented, was produced in England at a relatively inexpensive price, making the British version attractive to American buyers. The NHS was able to supply patients with the drug with relative ease when compared to the U.S. situation. Pentamidine was not the only case highlighting the struggle for treatments in the United States.

The drug AZT was the first drug developed to specifically treat the effects of AIDS. “AZT was heralded by some people as a miracle drug that would transform AIDS from a rapidly fatal disease to a chronic disease, and by others as a poorly tested, toxic drug whose profit generating capacity far exceeded its usefulness as a medical therapy” (Siplon 2002, p.21). AZT was developed by a private actor, the UK company Burroughs Wellcome (now part of Glaxo SmithKline after several mergers), but like many drugs

used to fight disease, its development was heavily dependent on government actors (FDA clinical trials) and government funds from the HHS (Siplon 2002, p.21). Phase I trials for AZT began on July 3, 1985; Phase II trials began in 1986. Phase III trials were waived to allow Burroughs Wellcome to concentrate on its new drug application (NDA). In January 1987, an FDA committee approved AZT with a ten to one recommendation (Siplon 2002, p.21-23).

Almost immediately following FDA approval, AZT became controversial, mainly due to the drug's cost. Burroughs Wellcome set the price for the antiretroviral drug at \$10,000 for a year's supply. On March 24, 1987 ACTUP NYC held its first protest against Burroughs Wellcome; approximately 250 people turned out to protest the cost of AZT. They also protested the fact that President Ronald Reagan had not publicly acknowledged the AIDS epidemic (Siplon 2002, p.19). Activists were not the only people questioning the cost of AZT. Prior to the protest, there was a Congressional hearing March 10, 1987 to discuss AZT pricing. The CEO of Burroughs Wellcome, T.E. Haigler Jr., defended the \$10,000 per year price as necessary. Representatives whose constituents were affected by AIDS such as Henry Waxman (D-Cal.) and Ron Wyden (D-Ore.) were outraged by Mr. Haigler's justifications. Representative Wyden asked, "Why didn't you set the price at \$100,000 per patient?" (Siplon 2002, p.23-24).

After several protests, Burroughs Wellcome lowered the price of a year's supply of AZT to \$8,000. In 1989 AZT was the only drug licensed to treat AIDS when it was found to be useful in caring for patients with HIV. This increased the market for AZT tenfold. In September 1989, Burroughs Wellcome brought down prices of AZT yet again

to \$6,500 for a year's supply amid protests by groups such as ACTUP London and San Francisco (Siplon 2002, p.24-25).

By mid-1989, AZT had been approved in 60 countries, including the United Kingdom, with the year's supply costing about 4,000 pounds (approximately \$7,800) (Small, 1993). The price of AZT set off similar protests in the UK by groups such as ACTUP London and the Terrence Higgins Trust. British health officials had conducted their own testing and approval process, although it was tested much more quickly than earlier testing procedures would have allowed (Small, 1993). This is because word had already spread from the USA that AZT was effective, and those already infected did not want to risk taking a placebo when a possible treatment was becoming more evident (Small, 1993).

The second HIV drug to be approved was ddI in 1991. In 1997, the U.S. federal government approved highly active antiretroviral therapy (HAART), also known as "the cocktail". U.S. Health and Human Services issued a set of recommendations that all PWAs should be on triple therapy, or HAART (Siplon 2002, p.35-36). In declaring HAART the standard of care, the federal government "was instructing itself to purchase the cocktail for the clients in its care" (Siplon 2002, p.36). Insurance companies now had to recognize this new standard as well.

Like the United States, HAART has become the standard in HIV care in England. In the UK, HAART has dramatically cut the number of deaths from AIDS since its introduction in 1996. When the combination of drugs was first introduced, death rates immediately fell by half. "Initially in 1996, only one in five people were given HAART, but that has risen swiftly as the impact of the drugs became apparent" (bbc.gov, 2003).

Despite the commitment of the NHS to provide all with health care there are still patients in the UK who do not have access. Julian Meldrum, from Aidsmap commented, "There are still some HIV patients in the UK who have unequal access to these treatments - mainly in the refugee and migrant communities" (bbc.gov, 2003).

In addition, many in these British communities do not know that they have been infected because they have not been tested. Martin Kirk of Terrence Higgins Trust said, "We must remember that of all the people who will die this year with AIDS-related illnesses, a third will do so just three months after diagnosis. This is because they tested too late for treatments to be effective. There is still work to be done to encourage people to test for HIV, and remind them that it needn't be a death sentence" (bbc.gov, 2003).

These two nations differ on one particular aspect of HIV/AIDS drug policy. The United States refuses to support the generic replicating of antiretroviral drugs. "The U.S. has maintained its opposition to the Brazilian approach of providing generically produced antiretroviral drugs to poor people in poor countries" (Siplon 2002, p.135). The USA refuses to advocate or fund the use of cheap generic drugs made in developing nations such as India, stating that the drugs are of a lower quality, even though the drugs have been evaluated and approved by the World Health Organization (Boseley, 2004).

At the XV International AIDS Conference held in July 2004, the Bush Administration made this point clear. However, British officials did not agree. At the same conference, UK International Development Minister Gareth Thomas publicly rejected U.S. policies concerning generic antiretroviral drugs (kaisernetwork.org, 2004). Thomas stated, "One of the reasons we work with the international community is that we think the WHO and other organizations have the technical expertise so that countries

through their ministries of health can make the decisions they want to about the drugs they use" (Boseley, 2004).

CHAPTER VII

PROSPECTS FOR ADDRESSING THE NEEDS OF EMERGING AT-RISK CLIENT GROUPS AND CONCLUSIONS

In the United Kingdom, tests for HIV antibodies became widely used in the mid 1980s. The results of these tests led researchers to identify three original at-risk groups: men who have sex with men, injecting drug users, and people who received treatment with contaminated blood products. After the original waves of testing in the 1980s, there was a decline in the rates of HIV diagnoses (avert.org). “To an uncritical observer it might seem that by the late 1990s, at least the “crisis” phase of the AIDS epidemic was over. Fatalities and AIDS-related illnesses were on the decline and there was a reduction in progressions from HIV to AIDS. However, there were new side effects, drug-resistant strains of HIV were developing, and treatment costs were becoming exorbitant” (Siplon 2002, p.35). Each year from 1990 through 1997 saw between 2,500-2,700 new diagnoses in the United Kingdom (UKDH, 2005). Since 1999, there has been an even larger increase in the number of HIV diagnoses in the UK. In 2004, at least 7,275 new infections were reported (UKDH, 2005).

In addition to the increase of HIV infections, new groups began to emerge as those most affected by the disease. Every year prior to 1998 saw homosexual males as the largest at-risk population (UKDH, 2005). In 1999, heterosexuals became the main exposure category in the nation. According to Yvette Cooper, Parliamentary Under Secretary of State for Public Health, “The major component of the rapid increase in HIV infections in recent years has been the rise in heterosexually acquired infections” (SHAP, 2001). Of the 7,275 new infections in 2004, 4,287 of these were heterosexually acquired

(UKDH, 2005). At the end of 2004, 58,300 adults in the UK were living with HIV. Of these adults, approximately 26,700 were heterosexuals (UKDH, 2005).

As heterosexuals are emerging as the most at-risk group in the UK, several sub-groups are also solidifying. In 2004, a total of 17,700 women were infected with HIV. Therefore, women represent 60% of all heterosexually acquired infections in the UK (UKDH, 2005). To further emphasize this point, we may point to male to female ratios of HIV diagnoses. Prior to 1989, the male to female ratio of HIV infections in the UK was more than 10 to 1. In 2004, that ratio had narrowed to 4 male to 3 female diagnoses (UKDH, 2005). Ethnic minorities are another emerging at-risk group in the United Kingdom. Of the 7,275 new HIV cases diagnosed in 2004, ethnic statistics were known and recorded for 5,787 (UKDH, 2005). Of the ethnicities reported, 36% were white, 53% black-African, 4% black-Caribbean, 7% other or mixed race (UKDH, 2005). It is evident then that women and ethnic black Africans have emerged as the most at-risk groups in the UK. In regard to AIDS, the total number of reported deaths in the UK is 20,440 as of 2004 (UKDH, 2005).

At the end of 2003, it was estimated that approximately 1,039,000 persons were living with HIV and 929,985 people had AIDS in the United States. Much like the UK data, information points to an increase in infections. "A study by the AIDS Research Institute of California-San Francisco (UCSF) scheduled to be released in March 2001 was leaked to AP reporter Laura Meckler in November 2000. The study revealed that, if anything, things had gotten worse" (Siplon 2002, p.38).

It was estimated that 43,171 AIDS cases were diagnosed in 2003; of these 43,171 diagnoses: 12,222 were white, 21,304 were black, 8,757 were Hispanic and 11,498 were

females (CDC, 2003). Cumulative deaths in the USA from AIDS through 2003 were estimated at 524,060 (CDC, 2003). It is obvious then that the scope of the AIDS epidemic has been far more damaging in the USA than in the UK. However, the trend of emerging populations is crucial to this comparison.

In the United States today, the majority of new HIV/AIDS diagnoses are the result of heterosexual sexual contact (CDC, 2003), a shift from the original primary risk activity of homosexual male sexual contact. Similar to the UK experience, there are several groups which have emerged as prominent at-risk populations. The first group is that of African Americans. According to the 2000 U.S. Census, African Americans comprise 12.3% of the population, “yet they have accounted for 368,169 (40%) of the estimated AIDS cases diagnosed since the epidemic began” (CDC, 2003). In 2003, African Americans accounted for 16,165 (50%) of the 32,048 new HIV/AIDS diagnoses in the 32 states with confidential HIV reporting (CDC, 2003). During 2000-2003 HIV/AIDS rates for African American males were 7 times those for white males and 3 times those for Hispanic males (CDC, 2003). In 2001, HIV/AIDS became one of the top 3 causes of death for African American males aged 25-54 years in the USA (CDC, 2003).

Women and African American women in particular, have also become an increasingly at-risk population. From 1999 through 2003, the annual number of estimated AIDS diagnoses increased 15% among women and increased only 1% among men (CDC, 2003). As of 2003, 170,679 women were diagnosed with AIDS, which represents about one fifth of the total AIDS diagnoses in the United States. The leading cause of HIV infection among women was heterosexual contact, followed by injection drug use (CDC, 2003; Patel and Rushefsky, 1999). African American women have

become significantly more at risk since 1999. During 2000-2003, HIV/AIDS infection rates for African American women were 19 times that of white females, and their infection rates were the second highest behind African American males (CDC, 2003). “Further, African Americans are less likely to have health insurance at the same time that they are at a greater risk of getting AIDS” (Patel and Rushefsky, 1999, p. 149; U.S. Department of Health, 1991). Since 2001, HIV/AIDS has become the number one cause of death for 25-34 year old African American women (CDC, 2003).

Using these statistics we find a similar pattern of emerging at-risk populations in both the UK and USA. Women and minorities have become those increasingly infected with HIV/AIDS. This is not surprising given that these populations also tend to have high rates of poverty in both nations. Researchers of HIV/AIDS knew this would be the case early in the epidemic. Neil Small commented in 1993, “Epidemiologically, we see a shift – first to injecting drug users and then into an increasingly less defined series of populations – AIDS will become a disease of poverty throughout the world” (Small, 1993, p. 7).

A major difference between the U.S. and UK is the federal versus unitary structure of government. The U.S. federal system provides interest groups with opportunities to lobby at the local, state and national level. Thus, the less structured lobbying system allows more points to influence and inform officials (Small, 1993). While this structure benefits various interest groups with the resources to lobby officials at each level, it creates competition for limited funding. Allocations to social service organizations are generally made according to need, however, those groups which are already well organized and funded are more equipped to express and demonstrate their

demand for resources. Emerging at-risk populations are fragmented in both nations, but in the context of lobbying, the groups fare much worse in the United States. While there are several allocations to female and minority-based HIV/AIDS programs they lack the ability to compete with general, well-established groups such as People with Aids (PWA) or the various chapters of AIDS Coalition to Unleash Power (ACT UP).

A second important factor as to why the UK will be able to provide emerging at-risk populations with more rapid allocations in funding and care is the lack of a cohesive gay movement or community (Small, 1993). In the USA, the gay community was a major force in creating and changing “almost all of the policies that have evolved to address AIDS... the gay community decided to take an active role in policy formation” (Siplon, 2002, p. 8). Despite the massive accomplishments of this socially stigmatized group, it may hurt emerging at-risk populations in the U.S. for two reasons. Because of early associations of AIDS with gay men, many people believed that AIDS was someone else’s problem (Small, 1993). This concept of HIV/AIDS as a “gay man’s disease” is still prevalent in U.S. culture, particularly in the emerging at-risk groups (Small, 1993).

The second reason a cohesive gay movement may impede at-risk populations relates to the competition for limited resources. As previously noted, gay community organizations in the U.S. have a prominent history in AIDS policy, and are well-organized and well funded. In the UK, gay culture is more fragmented and did not coordinate efforts on the level of gay-community organizations in the U.S. Researcher Simon Watney commented, “British gay culture is atomized... unable even to organize a proper national newspaper” (Small, 1993, p.73) Due to the lack of a strong gay

community in the UK, this group was not able to secure a majority of funding, or influence policy to the extent that was seen in the USA (Siplon, 2002).

The final factor that will enable the UK to provide rapid preventative and medical care to these at-risk populations is the presence of a national health care system. The NHS receives funds directly from the government to be used for HIV/AIDS research, preventative program development, preventative education, and medical care for those diagnosed with HIV/AIDS. At-risk citizens receive medical care at no cost, and the UK has made a 47 million pound commitment to improving sexual health and preventative programs to at risk populations. While many may choose not to take advantage of these programs, it is more likely that people will participate in HIV/AIDS testing and sexual health programs when they are provided at no cost.

In the USA it is difficult for the government to funnel allocations directly into medical care for HIV/AIDS patients. Using the CARE Act as an example, funds were given to cities, states, and special projects for prevention. Much of these funds will be lost to administrative costs. Remaining funds are split between care for those who are already infected, and preventative programs. In addition, 40 million people in the United States are not covered by any health insurance, and thus many not be tested for HIV/AIDS until severe health problems persist. Many aspects of safe sexual health come at a cost in the U.S., especially to those who may need these products and services the most; condoms, contraceptives, regular check-ups, and STD/HIV/AIDS tests all carry significant costs to the millions without health insurance.

Conclusions

It is strikingly clear that women, African Americans, and ethnic black Africans in the UK are emerging as those populations most at-risk for HIV/AIDS. The governments of both nations have recognized that HIV/AIDS is becoming increasingly common in women, minorities, and those in poverty. Both nations are also attempting to address this problem with the allocation of funds, research, and preventative programs and strategies. In spite of these efforts, it will be difficult for the United States to reduce or stabilize HIV/AIDS rates in these populations for the reasons discussed above.

The lack of a national health care system, the presence of strong community organizations in comparison to the fragmented nature of emerging at-risk groups, and the federal structure of the USA, will continue to impede these groups most in need of resources from educating and protecting themselves. In contrast, the UK is able to allocate funds directly to the NHS and the nation lacks the level of competition for HIV/AIDS resources as seen in the USA. It is probable then, that the UK will continue to have far fewer cumulative HIV/AIDS infections than the USA, and that emerging infected populations are more likely to access the resources they need to remain healthy.

However, there is hope that emerging populations will be able to gain some access through the existing structure in the United States. For example, in 1987, the “two largest ACTUP chapters were NYC and San Francisco, but the largest chapter today is ACTUP Philadelphia. Over one half of members are people of color, mainly from the low income areas of the city” (Siplon 2002, p.8-9).

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