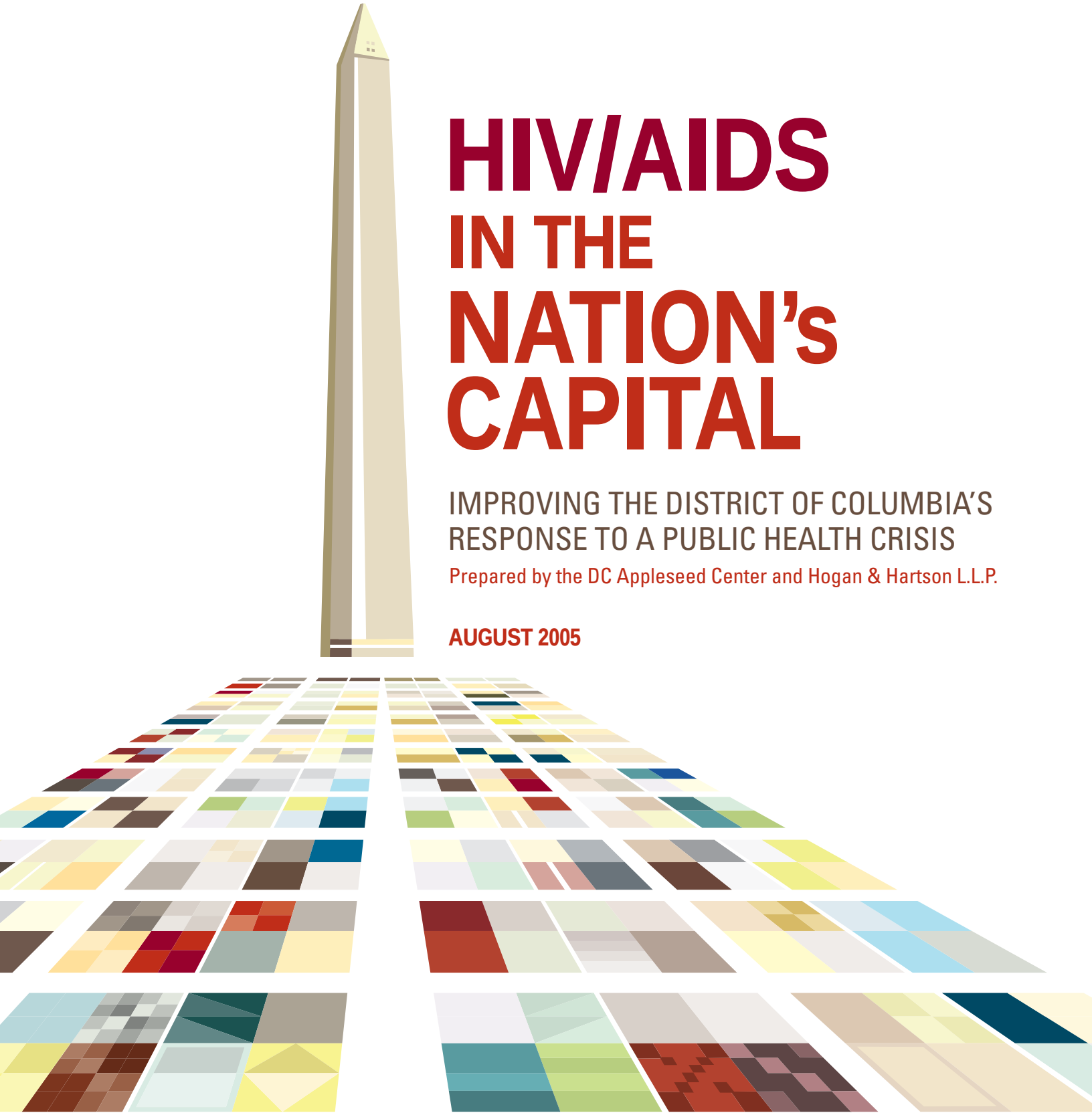

HIV/AIDS IN THE NATION's CAPITAL

IMPROVING THE DISTRICT OF COLUMBIA'S RESPONSE TO A PUBLIC HEALTH CRISIS

Prepared by the DC Appleseed Center and Hogan & Hartson L.L.P.

AUGUST 2005

DC APPLESEED
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The cover art is an original

artistic rendition by Leigh Cullen of the **NAMES Project AIDS Memorial Quilt**™ on the National Mall in Washington, D.C. Originally conceived in 1985, the Quilt consists of panels commemorating the lives of thousands of individuals who have died of AIDS. Each memorial panel is created and sewn by the individual's friends and family members. The Quilt has been displayed in its entirety in Washington, D.C. four times, most recently in 1996 on the Mall. More information on the Quilt is available at **http://www.aidsquilt.org/**. The NAMES Project Foundation is not affiliated with DC Appleseed and had no involvement in the preparation of this report.

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The DC Appleseed Center works on issues affecting the daily lives of those who live and work in the District of Columbia area – from health care to voting representation to education reform to environmental concerns to jobs and housing. We work with volunteer attorneys, business leaders and community experts to identify the issues, conduct research and analysis, make specific recommendations for reform, and advocate effective solutions. Our experienced staff organizes project teams and leverages thousands of hours of pro bono time.

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EXECUTIVE SUMMARY

INTRODUCTION

The District of Columbia's response to the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) epidemic lags far behind that of many other cities across the nation. According to a high-ranking District official, the District is in some respects 10 to 15 years behind where it should be in mounting a concerted, effective response to the disease. Even though many individuals, government officials, and nonprofit organizations have devoted considerable time and resources to addressing HIV/AIDS in the District, the disease continues to devastate District residents.

The District's annual rate of new AIDS cases is over 10 times the national average and is believed now to be the *highest of any major U.S. city*. Through the end of 2003, approximately 16,500 District residents had been diagnosed with AIDS, resulting in over 7,000 deaths. Today, over 9,000 District residents are living with AIDS. That is nearly *1 out of every 50 people* in the District. Moreover, HIV/AIDS is one of the most severe health problems facing the District, both in terms of disability and lost lives.

Unfortunately, even these numbers fail to capture the extent of the epidemic because they do not include HIV-positive people in the District who have not developed AIDS. Given that the District's incidence of AIDS is among the highest in the country, the District likely has one of the highest rates of new HIV infections. While the precise number of District residents infected with HIV is unknown, District public health officials estimate that *1 out of every 20 District residents* is infected. Even more alarming is the fact that thousands of these individuals do not know that they are infected or that they may infect others.

In light of these circumstances, at the request of the Washington AIDS Partnership and with the support of Mayor Anthony Williams, DC Appleseed has examined how the District government is managing the city's HIV/AIDS epidemic – including efforts to educate the public, prevent further spread of the disease, and care for infected individuals. DC Appleseed attempted through its investigation to address the question posed by Mayor Williams in an interview this spring: "We have huge incidence of HIV/AIDS. We spend a lot of money on it. How can we better focus our resources to get more mileage on something that's killing too many people?"

Unfortunately, as this report explains, there are no simple answers to the Mayor's question. But several things are clear:

- the District is not systematically collecting and analyzing data about the epidemic in a way that would allow it to plan prevention and care effectively;
- the District is not sufficiently coordinating and supervising the government agencies and private organizations that provide services for individuals living with HIV/AIDS;
- the District's general prevention efforts need improvement; and
- the District's HIV/AIDS services are insufficient for certain populations, including youth in the public schools, drug users, and the incarcerated.

In each of these four areas, this report makes specific findings and recommendations that, taken together, should ameliorate the HIV/AIDS crisis facing this city. Rather than calling for drastic government reorganization in order to improve the District's response to the HIV/AIDS epidemic, DC Appleseed suggests measures that can be implemented within the existing agency structure. DC Appleseed

is mindful that there may be costs associated with some of the report's recommendations, although a number of the recommendations may be implemented without significant additional expense to the District. Where possible, DC Appleseed comments on the fiscal impact of its recommendations.

In addition, we believe an overarching step needs to be taken – specifically, DC Appleseed urges District leadership, including the Mayor, the City Administrator, the Deputy Mayor for Children, Youth, Families, and Elders, and the Director of the District's Department of Health (DOH), to clearly, forcefully, and publicly make the HIV/AIDS epidemic a top public health priority in the District. Such a step will help ensure that the necessary reforms occur and will galvanize support within the government and the community.

Although DC Appleseed spent considerable time examining many factors essential to addressing the Mayor's question, we do not purport to have thoroughly investigated all the elements of the governmental response to the epidemic. In fact, there are significant issues that merit in-depth review that could not be adequately addressed in this report, including HIV/AIDS services for District residents in Wards 7 and 8, housing for individuals living with HIV/AIDS, and the administration of the D.C. Healthcare Alliance (Alliance) program.

DC Appleseed is grateful for the cooperation of the government and the community during the preparation of this report. In addition, DC Appleseed appreciates the feedback received from numerous government officials, health experts, providers, and persons living with HIV/AIDS on the draft of the report. Everyone who reviewed the report expressed enthusiasm for working together to address the epidemic, including the Deputy Mayor for Children, Youth, Families, and Elders, as noted in his letter attached in Appendix A. Finally, and most importantly, DC Appleseed looks forward to working with the government, providers, and others in helping to implement the recommendations contained in this report.

SUMMARY OF REPORT

This report is composed of two parts. Part One provides information on the epidemiology of HIV/AIDS and the federal and local government agencies that respond to the disease. Part Two consists of seven chapters that make detailed findings and numerous recommendations about key aspects of the District's response to the epidemic. The first four chapters include information on HIV and AIDS surveillance, funding and grant management, prevention, and treatment and care. The final three chapters discuss three populations that require additional specialized attention: youth, drug users, and the incarcerated. The main recommendations of these seven chapters are as follows:

HIV AND AIDS SURVEILLANCE

The District's HIV/AIDS Administration (HAA) should collect and publicly release comprehensive HIV and AIDS data. The dissemination of data – including the particular populations infected with HIV, how they became infected, and whether they suffer from other chronic illnesses – is critical to understanding the scope of the HIV/AIDS epidemic. Timely epidemiological data provide the foundation for public health agencies to allocate funding and develop effective prevention and treatment strategies. Unfortunately, the District's surveillance program has severe shortcomings.

First, the HIV test result data the District has collected for almost four years remain undisclosed. Although the District makes public the number of District residents who have developed AIDS and how these residents were originally infected with HIV, the District has not disseminated the HIV test result data. Because individuals infected with HIV now can live ten years or more before developing AIDS, HIV data more accurately reflect the current state of the epidemic than do AIDS data. Not having access to these crucial data handicaps policy makers who are responsible for HIV/AIDS prevention and care programs because, as noted above, the total number of District residents infected with HIV is unknown.

Millions of dollars are being distributed for services and interventions based on outdated and incomplete data.

The Surveillance and Epidemiology Division (Surveillance Division) of the DOH's HAA, which is responsible for collecting and analyzing HIV/AIDS data and disseminating epidemiologic profiles for the city, has suffered from a lack of permanent leadership and has a staff vacancy rate of greater than 50 percent. The absence of continuous, effective leadership and resources has had a significant negative impact on the Surveillance Division's ability to fulfill its responsibilities, including collection and dissemination of comprehensive HIV and AIDS data.

FUNDING AND GRANT MANAGEMENT

The District should improve coordination and supervision of funding for HIV/AIDS services. Various publicly-funded programs provide financial assistance to cover the cost of certain HIV/AIDS services. These programs – which include Medicaid, the Alliance, and specific programs for people living with HIV/AIDS such as the AIDS Drug Assistance Program (ADAP) – use separate enrollment procedures, which can lead to duplicate enrollment or failure to enroll eligible individuals.

Enrollment difficulties and errors may disrupt the receipt of needed benefits and result in inefficient use of funding resources. For example, according to the District's Medical Assistance Administration, in 2001, over 1,000 individuals were enrolled in both the Alliance and the District's Medicaid program. This type of duplicate enrollment needlessly wastes the District's resources, since federal funding should be covering the majority of the health care costs of these individuals. Further, failure to enroll eligible individuals in programs such as ADAP can have severe consequences. In fact, for many HIV-infected individuals, enrollment in ADAP is the only way to receive and to pay for life-prolonging HIV drugs.

To avoid these problems, the District should develop a centralized application process for enrollment and eligibility verification for publicly-funded health care programs. Of the programs available to persons with HIV/AIDS in the District, Medicaid offers the best combination of services for beneficiaries and is the most cost-effective for the District. Medicaid enrollment should therefore be maximized.

HAA should improve the management of its grants to private HIV/AIDS service providers. The District should improve its grant management process and use available funding more efficiently. Chronic payment delays have hindered the provision of services by community-based organizations (CBOs) and have put unnecessary financial pressure on these providers. The Council of the District of Columbia (D.C. Council) and the Office of the Inspector General (OIG) recently focused attention on this issue, and there are indications that HAA is streamlining its grant payment process. HAA should ensure that grants are paid promptly and should evaluate the effectiveness of its new payment procedures on an ongoing basis. HAA should also address continuing problems with grant approvals and renewals and burdensome reimbursement requirements that jeopardize the provision of HIV/AIDS services.

HIV PREVENTION

HIV testing and counseling should be offered as a routine part of all medical care. The Centers for Disease Control and Prevention (CDC) estimates that almost one quarter of those living with HIV nationwide are unaware that they are infected. Studies indicate that individuals who know that they are HIV-positive are more likely to change their behavior to reduce the risk of spreading the infection to others and to seek appropriate care and treatment for themselves. More people likely would undergo HIV testing and learn their status if HIV testing were routinely offered as part of medical care.

DOH should promote routine HIV screening by all health care providers, including private doctors and medical facilities. The District Medicaid program and the Alliance should strongly encourage providers to offer HIV testing and counseling as a routine part of primary medical care. DOH should implement routine testing and counseling at its own health care facilities, including the facilities serving high-risk populations such

as substance abuse treatment facilities, the District's Sexually Transmitted Disease (STD) Clinic, and the Tuberculosis (TB) Clinic. All those tested should receive their HIV results immediately to ensure that they know their HIV status, take measures to change their behavior, and, if infected with HIV, enter appropriate treatment and care.

HAA should significantly expand condom distribution efforts. Condom use is one of the most basic and universally recognized prevention interventions to reduce HIV transmission. When used correctly, condoms greatly reduce the risk of transmitting and contracting HIV. HAA should significantly expand condom distribution efforts in the District, using a variety of venues, including government offices, health offices, and bars. HAA should develop centralized mechanisms for all providers of HIV/AIDS services to obtain free or reduced price condoms. HAA should also coordinate with District agencies serving high-risk populations, such as drug users and the mentally ill, to develop a system to increase condom availability among these groups.

HIV/AIDS TREATMENT AND CARE

HAA should coordinate with agencies serving HIV-positive individuals who also have other serious illnesses. People living with HIV/AIDS often suffer from other diseases such as mental illness, drug addiction, hepatitis C, and TB. These other diseases may complicate HIV treatment, making HIV prevention and coordination of care even more problematic.

Coordination between HAA and other relevant District agencies currently is limited, and the lack of coordination can have severe consequences. For example, HIV testing is not routinely offered at all substance abuse treatment facilities, the STD clinic, the District's TB clinic, or sites serving individuals with mental illness. Individuals seeking care and treatment at these facilities are more likely to be infected with HIV than others. Missed opportunities to inform individuals of their HIV status increases the risk of others being infected. By cooperating with agencies and providers serving individuals with multiple illnesses, HAA could greatly improve its outreach to high-risk and HIV-positive individuals.

HIV PREVENTION IN THE D.C. PUBLIC SCHOOLS

D.C. Public Schools (DCPS) should develop and apply standards for HIV prevention education. Youth in the District face serious risk of HIV infection due to above-average rates of unprotected sex and substance use. This risk is compounded by the misconceptions young people often have about health risks associated with HIV/AIDS and methods to protect themselves from HIV transmission. District youth would therefore benefit from a more coordinated system of HIV prevention education. Yet, there are currently no school-wide standards for the quality or content of HIV/AIDS education and no means of tracking which students have received HIV/AIDS education. The Board of Education and DCPS, in collaboration with HAA, should develop system-wide comprehensive standards regarding HIV prevention education.

HIV PREVENTION AMONG DRUG USERS

The District should expand substance abuse treatment opportunities and improve existing syringe exchange programs. Available data demonstrate that substance abuse treatment is a proven HIV prevention strategy. Injection drug users who do not enter treatment are up to six times more likely to become infected with HIV than those who enter treatment and do not resume drug use. The District's own reports have found that existing substance abuse treatment programs do not meet the current demand of addicted individuals seeking treatment. The District should increase the availability of substance abuse treatment programs.

Further, injection drug users who share syringes and other injection equipment and practice unsafe sex are at high risk of contracting and spreading HIV and other blood-borne infections. Approximately one-third of the District's AIDS cases are attributed to injection drug use. The District estimates that there are approximately 10,000 active injection drug users in the District today. Distributing sterile injection

equipment, especially when done in connection with complementary services such as HIV testing and counseling, prevention case management, and drug treatment referrals, mitigates the adverse consequences of injection drug use by reducing HIV transmission.

Although Congress has barred the District from using public funds to support the distribution of sterile injection equipment, HAA may lawfully fund complementary HIV/AIDS services provided by the existing authorized syringe exchange program. HAA should ensure that District-run programs and CBOs that provide HIV/AIDS services collaborate and co-locate with existing syringe exchange programs – thereby enhancing HIV prevention among the District's drug users without violating the congressional ban. Finally, the District government and advocates should continue efforts to persuade Congress to permit the use of local funds to support life-saving programs that distribute sterile syringes.

HIV/AIDS AMONG THE INCARCERATED

The Department of Corrections (DOC) should expand substance abuse treatment programs for the incarcerated. The vast majority of incarcerated individuals have a history of substance abuse, which puts them at high risk for HIV. Correctional facilities in the District offer a substance abuse treatment readiness program with a capacity for only 80 inmates, and a substance abuse treatment program that can accommodate only 60 inmates. Since the District has over 3,400 inmates in custody in local detention facilities on a daily basis, the capacity of the substance abuse treatment programs is severely deficient. DOC should expand its substance abuse treatment program as an HIV prevention measure.

The DOC should ensure that HIV-positive inmates receive a 30-day supply of HIV medication when released from custody. It is critical to the health of inmates on HIV medication that they continue their treatment regimen uninterrupted upon release. HIV develops resistance to drugs rapidly, so poor adherence to HIV medication can result in an individual developing a drug-resistant form of HIV. Drug-resistant HIV can be transmitted to others and also limits treatment options for infected individuals. Because it may take a significant amount of time after release from incarceration to locate a health care provider, an inmate needs to receive a sufficient supply of medication at discharge. Currently, DOC provides only a 7-day supply of medication upon release. Federal funding is available to finance HIV medication for inmates upon release. DOC should use federal funds to increase the medication supply provided at discharge. Unscheduled releases and poor internal communication result in the release of inmates without medication. DOC should ensure that HIV-positive inmates are not released without adequate medication and a referral to a doctor; failure to do so puts both the recently incarcerated and others at risk.

CONCLUSION

As Mayor Williams recently noted, the District has devoted significant resources to fighting HIV/AIDS – far more, in fact, than the District has devoted to many other public health issues. Yet the District's annual AIDS incidence continues to rise and is one of the highest in the nation.

On numerous occasions, the authors of this report have asked key stakeholders in the District's system of HIV/AIDS care and prevention how the HIV/AIDS epidemic has reached such massive proportions in the nation's capital. The answer to this question was often the same: lack of effective, consistent leadership. This lack of leadership is evident in the following:

- the true extent of the HIV/AIDS epidemic in the District is unknown;
- HIV/AIDS services in the District are not coordinated to the degree necessary to be effective;
- funding for HIV/AIDS prevention and care in the District is not being distributed in a timely manner or being used as effectively and efficiently as possible; and
- the District does not effectively target services where they could make a significant difference – among students, drug users, and prisoners.

HIV/AIDS is a complicated disease both to prevent and to treat. Controlling it takes more than money; it requires determination and commitment from the government and the community. The risk-taking behaviors that lead to the transmission of HIV – sexual activity and drug use – are difficult behaviors to change but are not often discussed openly by public officials. The reality is that the HIV/AIDS epidemic is getting worse in the District, not better. The District government should do more to address this crisis, and it has the tools at hand to do so.

The District has a dedicated network of providers addressing this disease and its devastating impact on our community. These providers strive to educate, prevent, and treat those at risk for and infected with HIV. Their efforts deserve the unflagging support of the government and the public at large. District leaders are in a unique position to rally this support, and they should do so.

DC Appleseed urges the leadership of the District to speak frequently, strongly, and clearly about HIV/AIDS in our community and to take committed and strategic steps to improve the management of this epidemic. This challenge is of life-and-death importance. Effective prevention, testing, and treatment of HIV/AIDS depend on an informed public, and government leaders can play a crucial role in educating the community about the epidemic. But in addition to raising awareness about HIV/AIDS, the Mayor, City Administrator, Deputy Mayor, and the Director of DOH should take responsibility for ensuring that HAA has the necessary staffing and resources, is effectively managed, and coordinates with other government agencies to address the needs of special populations. Simply put, business cannot go on "as usual." The District's efforts to address HIV/AIDS have fallen far short, and addressing the epidemic must move front and center as a priority of District government.

With the appropriate attention and commitment, the District can substantially improve its response to this urgent public health issue. This report provides detailed analysis and a list of specific recommendations concerning the needed response, but it is only the first step. DC Appleseed is prepared to assist in the implementation of the recommendations in this report, and to join with District leaders, CBOs, and others in that effort. This disease is not likely to be eradicated, but with the commitment and public support of District leaders, we can reduce its terrible toll.

REPORT STRUCTURE AND METHODOLOGY

REPORT STRUCTURE

The report is divided into two parts: (1) Background of the HIV/AIDS Epidemic and (2) Findings and Recommendations Concerning the District's Response to the HIV/AIDS Epidemic. The report also includes appendices containing a letter to the Project Team from Deputy Mayor Albert, a list of recommendations, recommendations for improving the District's web-based HIV/AIDS resources, and information regarding eligibility requirements for certain publicly-funded health coverage programs in the District. In addition, a list of acronyms is available on the back cover of the report.

PART 1: BACKGROUND OF THE HIV/AIDS EPIDEMIC

This part includes chapters on epidemiology and government structure.

- **Chapter I: Epidemiology.** The chapter examines current data about the HIV/AIDS epidemic in the District.
- **Chapter II: Government Structure.** The chapter presents an overview of the federal and District agencies and programs, CBOs, and the health care providers that furnish prevention and care services for HIV/AIDS in the District.

PART 2: FINDINGS AND RECOMMENDATIONS CONCERNING THE DISTRICT'S RESPONSE TO THE HIV/AIDS EPIDEMIC

This part includes chapters on HIV and AIDS surveillance, funding and grant management, HIV prevention, and treatment and care. In addition, this part discusses HIV prevention in the public schools, HIV prevention for drug users, and HIV/AIDS among the incarcerated.

- **Chapter III: HIV and AIDS Surveillance.** Surveillance is the means by which public health agencies track the incidence of HIV and AIDS. Incidence data are necessary to allocate federal and local funding and to formulate effective treatment and prevention strategies. Chapter III provides background information on HIV and AIDS surveillance in the District. The chapter highlights the importance of surveillance data and analysis and identifies current deficiencies in the District's system for collecting, analyzing, and presenting timely surveillance data.
- **Chapter IV: Funding and Grant Management.** HIV/AIDS services are funded by many agencies, including the federal government, the District government, and private grants and donations. The chapter describes three critical publicly-funded programs: Medicaid, the Alliance, and Ryan White CARE Act programs. Chapter IV also describes the challenges facing these programs and how the District's efforts to expand health care coverage for persons with HIV/AIDS have been hampered by poor coordination among agencies and inefficient use of funds. The chapter concludes by discussing HAA's grant management process and the need for a comprehensive quality assurance program.
- **Chapter V: HIV Prevention.** Continuous surveillance of the epidemic and an understanding of relevant risk behaviors are necessary to formulate effective prevention interventions. Prevention efforts are a critical component of a comprehensive response to the HIV/AIDS epidemic. The chapter examines the District's approach to preventing the spread of HIV, provides an overview of scientifically-tested HIV prevention interventions, and describes prevention programming.
- **Chapter VI: HIV/AIDS Treatment and Care.** Many people living with HIV/AIDS struggle with multiple needs. Proper health care, housing, food, income, and transportation are particularly important in order to effectively manage and treat individuals living with HIV/AIDS. However, substance use and addiction, mental health problems, limited access to health care and support services, and poverty often result in these needs being unmet. The chapter describes the care and services required by individuals living with HIV/AIDS and the type of services provided by the District.
- **Chapter VII: HIV Prevention in D.C. Public Schools.** Many young people have misconceptions about the health risks associated with STDs and HIV/AIDS, as well as incomplete or erroneous

information on prevention measures and the need for testing. Therefore, a targeted and comprehensive HIV prevention program is imperative to provide young people with the skills and information to protect themselves. The chapter describes the HIV prevention programs that exist within the D.C. Public Schools (DCPS) and makes recommendations to strengthen these programs.

- **Chapter VIII: HIV Prevention among Drug Users.** Research has shown that the most effective approach for preventing the spread of HIV in drug-using populations is a comprehensive strategy that includes community-based outreach, drug abuse treatment, and sterile syringe access programs – all in combination with testing and counseling for HIV. The chapter includes recommendations for the improvement of substance abuse treatment and HIV prevention services among the District's population of drug users.
- **Chapter IX: HIV/AIDS Among the Incarcerated.** The rate of AIDS cases among the incarcerated in the U.S. is three times higher than the AIDS rate among the general population in the United States. The incarcerated are isolated from the mainstream system of prevention and care while they await trial or serve their sentences. Detention presents an opportunity for targeted prevention and care services prior to their release to the community. The chapter explains HIV/AIDS services for the incarcerated and ex-offenders in the District and makes recommendations for improving these services.

METHODOLOGY

DC Appleseed, an advocacy organization that addresses serious local issues, organized a Project Team to research and analyze the District's response to HIV/AIDS and prepare this report.

PROJECT TEAM

A team of volunteers at the law firm of Hogan & Hartson L.L.P. partnered with DC Appleseed to conduct the research and writing of this report. Hogan & Hartson provided its services *pro bono*. Because of existing relationships in its education practice, Hogan & Hartson did not assist in the research or drafting of the chapter on HIV Prevention in the D.C. Public Schools.

In addition, DC Appleseed convened an expert panel and a stakeholder panel to advise the Project Team in conducting research and formulating findings and recommendations.

EXPERT PANEL

The members of the expert panel, who participated in the project *pro bono,* are: Nicole Lurie, M.D., M.S.P.H., a physician/ researcher at RAND Corporation; Dr. Charles Turner, Ph.D., a behavioral scientist with the City University of New York and the Research Triangle Institute; Mary Young, M.D., Director of the Women's Integrated HIV Study at the Georgetown University Medical Center; and Jonathan Zenilman, M.D., Chief of Infectious Diseases at Johns Hopkins Bayview Hospital. The Project Team also consulted with Tim Westmoreland, J.D., Research Professor at the Georgetown University Health Policy Institute.

STAKEHOLDER PANEL

With the assistance of Robert Washington, Ph.D., a psychologist and former Director of the District's Department of Mental Health (DMH), DC Appleseed convened and facilitated a stakeholder panel that included representatives from the following groups: HIV-positive individuals; HIV/AIDS service providers; mental health providers; HIV prevention services organizations; faith-based organizations; and advocacy groups for the incarcerated, transgender community, and sex workers. A number of the stakeholders are employed by organizations that receive funding from HAA. The panel has been instrumental in informing DC Appleseed's research and writing. The following is a list of panel members:

- **Jeffrey Akman**, M.D., Chairman, Department of Psychiatry and Behavioral Sciences, George Washington University
- **Philippe Chiliade**, M.D., Medical Director, Whitman-Walker Clinic

- **Lawrence D'Angelo**, M.D., M.P.H., Division Chief, Adolescent Medicine, Children's National Medical Center
- **Philip Fornaci**, J.D., Executive Director, D.C. Prisoners' Legal Services Project
- **Earl Fowlkes**, Executive Director, DC CareConsortium
- **Susan Galbraith**, Executive Director, Our Place DC
- **Robert Keisling**, M.D., Director of Mental Health, Unity Health Care
- **Bernadine Lacey**, RN, Ed.D., Former Executive Director, Children's School Services, Children's National Medical Center
- **Patricia Nalls**, Executive Director, The Women's Collective
- **Candace Shultis**, Pastor, Metropolitan Community Church
- **Catalina Sol**, Director, HIV/AIDS Program, La Clinica del Pueblo
- **Adam Tenner**, Executive Director, Metro Teen AIDS
- **G.G. Thomas**, Client Advocate & Program Assistant, Helping Individual Prostitutes Survive
- **Jay White**, Board of Directors, Us Helping Us
- **Christine Wiley**, Pastor, Covenant Baptist Church

INTERVIEWS AND SITE VISITS

The DC Appleseed HIV/AIDS Project Team interviewed approximately 150 individuals, including Gregg Pane, M.D., Director of DOH, Lydia Watts, Director of HAA, and virtually all division heads at HAA. The Project Team also met with officials from the Addiction Prevention and Recovery Administration (APRA), DCPS, the DOC. In addition, the Project Team also interviewed numerous providers, consumers, public health experts, and advocates who work directly with persons living with and at risk for HIV and AIDS in the District. Finally, the Project Team toured the facilities of many care and prevention service providers.

Interviews with District government officials and representatives from community organizations are referenced on an anonymous basis in the report.

FOCUS GROUPS

The Project Team conducted various focus groups with HIV-positive individuals and drug users. These groups included individuals of various age groups and different genders, as well as a cross-section of income levels.

PUBLIC HEARINGS, MEETINGS, AND EVENTS

In order to obtain a broader understanding of issues involved, the Project Team attended numerous public hearings and meetings, including Congressional hearings, D.C. Council hearings, meetings of the Mayor's Advisory Committee for HIV/AIDS, HIV Prevention Community Planning Group meetings, Ryan White Planning Council meetings, World AIDS Day events, public roundtable meetings, and community events.

DOCUMENT REVIEW

The Project Team reviewed thousands of pages of documents, including reports, legislation, budgets, studies, policies, and meeting minutes.

BENCHMARKING

Where appropriate, the Project Team identified model practices in other jurisdictions. When pertinent, these are identified in the body of the report.

VETTING PROCESS

DC Appleseed received comments on drafts of this report from numerous individuals, including members of the Project Team's expert and stakeholder panels, the DC Appleseed Board of Directors, District government officials, members of the D.C. Council, and other interested individuals and organizations. The content of the final report reflects feedback from these individuals.

PART 1

BACKGROUND ON THE HIV/AIDS EPIDEMIC

Before examining the system of care and prevention for HIV/AIDS in the District, it is necessary to outline the magnitude of the problem. After explaining the epidemiology of HIV and AIDS, this section describes the epidemic, both on a national and local level, in terms of common modes of transmission and high-risk populations.

INTRODUCTION[1]

HIV AND AIDS

HIV is a virus that damages and kills an infected individual's immune cells, particularly the CD4+ T-cells, which coordinate the body's immune response. About 70 percent of newly-infected people will experience initial symptoms similar to those of the flu: fevers, chills, night sweats, and rashes, which usually last for a few days. Within three to five days after infection, the virus travels to the lymph nodes, where it reproduces rapidly. As HIV progressively destroys the immune system, the body becomes vulnerable to opportunistic infections – caused by viruses and bacteria that are typically not harmful to people with healthy immune systems – as well as to certain cancers.[2]

Indicators of AIDS:

HIV infection with

- Low CD4+ T-cell count
- Specific diseases and conditions indicative of AIDS, such as certain types of pneumonia

Individuals with HIV are identified by testing for the presence of HIV antibodies, special proteins produced by the immune system to fight the disease. About 95 percent of people infected with HIV develop antibodies within three months after infection, and nearly all of those infected develop antibodies within six months.

When an HIV-positive individual's CD4+ T-cell count falls below 200 per cubic millimeter of blood (the normal range is 600 to 1,200), the individual meets the CDC's clinical definition for AIDS.[3] If an HIV-positive individual is diagnosed with one of 26 clinical conditions listed by the CDC, including certain types of pneumonia, he or she also meets the AIDS definition.[4]

TREATMENT OF HIV/AIDS

Recommended care for HIV-positive individuals changed dramatically in 1996, with the development of "highly active antiretroviral therapy" (HAART), a treatment that combined existing medications with new drugs that interfere with the replication of the virus.[5] Prior to the introduction of HAART, the CDC estimated that about half of the HIV-positive population would develop AIDS within 10 years after infection with the virus.[6] The progression time varies greatly across individuals due to a variety of factors, including pre-existing health status and behaviors.[7] With the introduction of HAART, the onset of AIDS in individuals infected with HIV has been significantly delayed.[8]

MODES OF TRANSMISSION

HIV is transmitted through the exchange of certain body fluids, including semen, vaginal secretions, breast milk, and blood. The major transmission modes are sexual contact (either homosexual or heterosexual), the sharing of syringes or other drug-injection equipment, mother-to-child transmission, and blood transfusions.

SEXUAL CONTACT

The most common mode of HIV transmission is sexual contact.[9] Some types of sexual contact, such as unprotected receptive anal sex, present a greater risk of transmission of the virus than others. For all sex acts, however, proper condom use has been shown to reduce the risk of contracting HIV.[10] The greater number of partners a person has, the greater is the exposure to potential HIV infection, particularly if safe sex practices are not employed with each sex act. Safe sex involves the use of condoms

during vaginal and anal sex and a protective latex barrier between the mouth and the vagina, penis, or anus during oral sex.

If a person is already infected with an STD, the chances of contracting HIV are higher. The increased risk of HIV infection may be due to the fact that an individual with an STD is engaging in unsafe sex, or may be because STDs such as syphilis, chlamydia, and gonorrhea appear to increase the body's vulnerability to HIV.[11] The increased risk of transmission may be due to open sores or breaks in the skin, as in the case of syphilis, or because of other effects of the STD.[12] STD infections in HIV-positive individuals may increase the viral load in the HIV-positive person's secretions, resulting in a greater risk of transmitting the disease to others.[13]

SUBSTANCE USE AND ABUSE

Substance use and abuse are linked with the transmission of HIV in two ways: through the sharing of needles and syringes infected with the virus, and through high-risk sexual behavior associated with the use of alcohol or drugs.[14]

Needle and syringe sharing can lead to exchange of blood and thus result in transmission of the virus.[15] Studies have shown that HIV can survive in used needles for over one month.[16] The relationship between injection drug use and HIV infection goes beyond the substance users and puts others at risk for contracting the disease. For example, an injection drug user (IDU) can spread the infection to a sexual partner through unprotected sex and a pregnant IDU may pass HIV to her fetus.[17]

Substance users are also at a higher risk for engaging in survival sex and sex for drugs, which may put them in greater danger of infection. Survival sex refers to the practice of selling one's body to obtain the basic necessities of life, such as food and shelter. Substance users may also engage in sex work in order to obtain drugs and may forego the use of condoms during sex.

Another risk factor for unprotected sexual behaviors and, consequently, HIV transmission, is alcohol use.[18] Studies of homosexual men have found an association between heavy alcohol use and increases in high-risk sexual behavior or decreases in condom use.[19] Among heterosexuals, studies have found alcohol use increases two to fourfold the likelihood of not using condoms.[20]

MOTHER-TO-CHILD TRANSMISSION

Mother-to-child HIV transmission is almost entirely preventable. If untreated, about one quarter to one third of HIV-positive women will transmit the virus to their babies during pregnancy or labor and delivery through mechanisms that remain unknown, or after birth through breastfeeding.[21] However, medical treatment exists that can dramatically reduce this transmission rate. With combination antiretroviral therapy and use of caesarean section when necessary, the risk of mother-to-child transmission is lowered to 1 to 2 percent.[22]

BLOOD TRANSMISSION

Historically, individuals receiving blood transfusions were at risk for HIV. Today, blood supplies are routinely screened for HIV, and pooled blood products are treated with heat to destroy the virus, rendering the likelihood of transmission through transfusions to about 1 in 1.5 million.[23]

Some risk of transmission through blood exchange still exists in certain situations. For example, if an individual has a bleeding cut in the mouth or the genital area, he or she is susceptible to HIV infection from an HIV-positive individual who also has a bleeding cut. Similarly, an emergency worker

Myths

Some people erroneously believe the following:

HIV can be transmitted by:

- Saliva
- Sweat
- Tears
- Urine
- Feces

HIV can be cured or prevented by:

- Drinking a bottle of vinegar
- Exercising regularly
- Eating garlic

National Institute of Allergy and Infectious Diseases, *HIV Infection and AIDS: An Overview* (Mar. 2005).

with an open cut could be exposed to an HIV-positive individual with a bleeding wound. HIV transmission can also occur, very rarely, through accidental needle sticks in a health care setting.[24]

CONTAMINATED NEEDLES

Contaminated needles used for steroids, silicone, and other injections may, as in the case of needle sharing by IDUs, lead to HIV infection. In addition, use of infected needles for tattooing and piercing may lead to transmission of HIV.[25]

THE EPIDEMIC IN THE UNITED STATES

The CDC estimates there have been a total of 929,985 reported cases of AIDS in the U.S. from 1981 through 2003, of which an estimated 524,060 resulted in deaths attributable to AIDS.[26] An estimated 1.1 million individuals are presently infected with HIV in the U.S.,[27] of which as many as one quarter may be unaware of their infection.[28] According to the CDC, of those infected with HIV, 405,926 people were living with AIDS in the U.S. in 2003.[29]

Definitions:

- Prevalence = proportion of persons with a particular disease within a given population at a given time
- Incidence = rate of new cases in a population during a specified time period

Clinical Epidemiology Glossary, available at http://www.med.ualberta.ca/ebm/define.htm (last visited July 23, 2005); D. Coggon et al., EPIDEMIOLOGY FOR THE UNINITIATED (4th ed. 1997), *available at* http://bmj.bmjjournals.com/epidem/epid.2.html (last visited July 23, 2005).

THE EPIDEMIC IN THE DISTRICT OF COLUMBIA

The District's AIDS rate has been estimated to be among the highest of urban areas in the country. As will be further explained in Chapter III, the District does not currently publicly disseminate HIV data. Due to the delay of the onset of AIDS, current AIDS data do not shed light on the incidence of recent HIV infections, particularly among those whose progression to AIDS may be slowed by antiretroviral therapy.[30] Thus, a comprehensive picture of the epidemic and a realistic estimate of the resources needed for care and services cannot be provided without HIV prevalence and incidence data; nevertheless, the existing AIDS prevalence and incidence data do suggest that the District HIV rates are likely to be extremely high when compared to other cities nationwide.

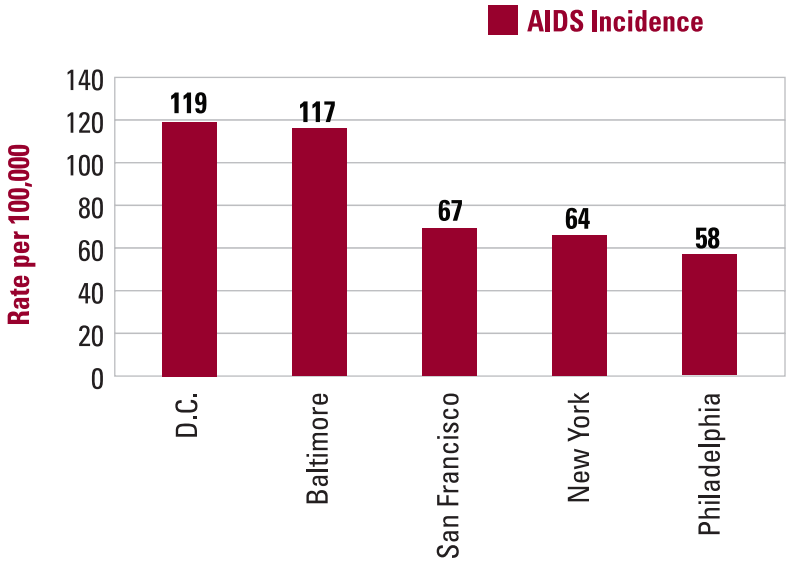
In the most recent year for which data are available, the District had the highest incidence of AIDS of all major metropolitan areas in the U.S. In 2003, the District had an AIDS incidence rate of 170.6 per 100,000 people.[31] This is an increase from the District's AIDS incidence rate in 2001, which at 119 cases per 100,000 people was the highest rate among cities with populations over 500,000.[32] In 2001, Baltimore had a comparable rate of 117 per 100,000, followed by San Francisco (67 cases per 100,000), New York (64 cases per 100,000), and Philadelphia (58 cases per 100,000).[33] Such comparative information is not available for more recent years.

According to the District's DOH, 9,375 individuals were living with AIDS in the District as of December 31, 2003.[34] There have been over 7,000 AIDS-related deaths in the District since 1984.[35] Similar to the national trend, the number of AIDS-related deaths in the District has been declining for the last 10 years, from its peak of 742 deaths in 1993 to 41 deaths in 2002.[36] The decreased number of deaths is attributable to the increased use of antiretroviral medication, which slows the progression of HIV to AIDS and lengthens the average time a person can survive with AIDS.[37] Despite advances in treatment, HIV/AIDS is one of the most severe health problems facing the District, both in terms of disability and lost lives.[38]

MODES OF HIV TRANSMISSION IN THE DISTRICT

Sexual contact is the most commonly reported mode of HIV transmission in the District. Injection drug use also plays an

2001 AIDS Incidence in Cities with Populations over 500,000



District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District of Columbia* 1 (Dec. 2003).

important role in transmission in the District. A significant number of persons living with AIDS are unaware of how they contracted HIV.[39]

Transmission Trends in the District

- Heterosexual contact is increasingly being identified as a mode of transmission, as is the case nationwide.
- The AIDS rate among women has been increasing.
- HIV continues to disproportionately affect people of color, particularly African Americans.

SEXUAL CONTACT

MEN HAVING SEX WITH MEN

Men having sex with men, or MSM, are at high risk for HIV. Male-to-male sexual contact is the most common mode of HIV transmission in the District.[40] African-American and Latino MSM are impacted by HIV/AIDS. Forty-six percent of African-American men with AIDS contracted HIV through male-to-male sexual contact.[41] For Latino men, that figure is 62 percent.[42] Factors such as poverty and inadequate access to health care can reduce access to prevention services, particularly for men of color.[43] Moreover, African-American and Latino MSM are less likely than white MSM to be tested for HIV or to seek treatment through programs targeting the homosexual and bisexual communities.[44]

HETEROSEXUAL CONTACT

Both men and women can contract HIV through heterosexual contact. Among the 2,028 women living with AIDS in the District in 2002, 44 percent identified heterosexual contact as their mode of exposure.[45] Many national studies indicate that the increase in the rate of HIV/AIDS among women may be due, in part, to the fact that many women are not aware of the high-risk behaviors of their sexual partners, meaning the sex or drug-use behaviors that may directly transmit

MSM: "Men having sex with men"

MSM include men who have sex with men but identify themselves as heterosexual, as well as men who identify themselves as homosexual or bisexual.

Men on the "down low"

The media report that, facing a stigma surrounding homosexuality in their communities, MSM may identify as heterosexual and conceal their sexual activity with men. These men, who are "on the down low," may continue to have unprotected sex with their girlfriends or wives, thus placing those women at risk for HIV infection. The "down low" phenomenon likely occurs among all races, and no scientific studies were found regarding its involvement in HIV transmission among any group.

See, e.g., Benoit Denizet-Lewis, *Double Lives on the Down Low,* N.Y. TIMES, Aug. 3, 2003, § 6 (magazine), at 28; Jose Antonio Vargas, *HIV-Positive, Without a Clue,* WASH. POST, Aug. 4, 2003, at B1.

HIV.[46] Some women believe they are in a monogamous relationship and do not require their partner to use condoms or engage in safe sexual practices because they are unaware of their partner's high-risk sexual or drug-related behavior.

PROSTITUTION, SURVIVAL SEX, AND THE SEX-FOR-DRUG TRADE

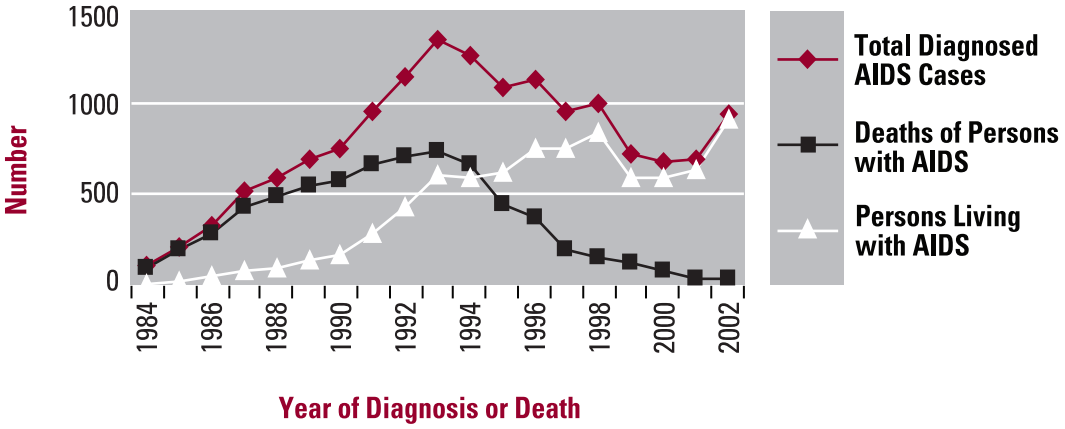
Commercial sex work, the exchange of sex for basic life necessities, and the exchange of sex for drugs also have been linked to HIV infection.[47] Estimates of the number of individuals involved in these activities in the District are unavailable.

SEXUALLY TRANSMITTED DISEASES

STDs are important indicators of risky sexual behavior and are likely to be significantly underreported. As is the case nationwide, there has been a slight increase in rates of syphilis, chlamydia, and gonorrhea in recent years in the District, particularly among men.[48] The incidence of these STDs continues to be far higher in the District than in the nation overall.[49] The high STD incidence among certain populations suggests continued engagement in high-risk behavior, and also may reflect increased susceptibility to HIV because of open sores or higher viral loads in secretions, as explained above.

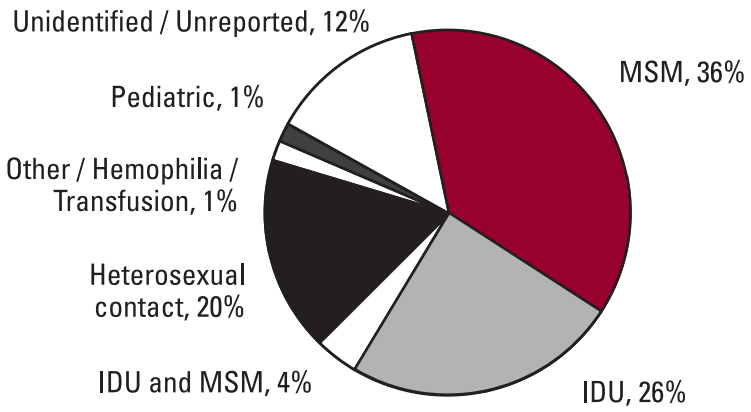
According to the CDC, youth (ages 10-19) and young adults (ages 20-24) are at higher risk for STDs than are other age groups. This increased risk may be due in part to multiple partners as well as to barriers to care and

Diagnosed AIDS Cases, Deaths, and Living AIDS Cases in the District by Year of Diagnosis (1984-2002)



District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District of Columbia* 18 (Dec. 2003).

Adult Living AIDS Cases in the District by Mode of HIV Transmission (Diagnosed Through December 31, 2004)



Total Living AIDS Cases = 9,110

Kompan Ngamsnga, Surveillance and Epidemiology Division, HIV/AIDS Administration, *Data for Decision Making, Epidemiological Data* 19, Presentation to the District of Columbia Ryan White Title I Planning Council (May 19, 2005).

prevention, including lack of insurance or financing and lack of transportation.[50]

SUBSTANCE USE AND ABUSE

Substance use and abuse is linked directly and indirectly to HIV transmission. HIV can be transmitted directly through the sharing of drug paraphernalia including syringes. In addition, drug and alcohol use can lead to risky sexual behavior.

Injection drug use is a common mode of HIV transmission in the District. In 2002, 23 percent of the men living with AIDS and 40 percent of women living with AIDS reported exposure to HIV through injection drug use.[51]

Substance abuse is a significant concern in the District. In September 2003, a report by the Mayor's Task Force on Substance Abuse Prevention estimated that approximately 60,000 District residents were "addicted to alcohol and other drugs."[52] Nearly 10,000 District residents are estimated to be IDUs.[53]

MOTHER-TO-CHILD TRANSMISSION

Only 1 percent of living AIDS cases in the District has been attributed to mother-to-child transmission.[54] However, between 1983 and 2002, 95 percent of all children under the age of 13 living with AIDS were infected with HIV through mother-to-child transmission. Of these cases, about 60 percent were diagnosed before the infant reached one year of age.[56]

RISK BY POPULATION GROUP IN THE DISTRICT

PEOPLE OF COLOR

HIV/AIDS has disproportionately affected the African-American community. Nationally, African Americans have the highest rate of new AIDS diagnoses among all ethnic groups. Locally, African Americans, who represent nearly 60 percent of the District's population, account for 75 percent of the

AIDS cases.[57] Moreover, the rate of new AIDS cases among African Americans has increased in recent years, even as the rate has decreased among other groups in the District.[58] In addition, between 1990 and 2002, 90 percent of the 13 to 19 year olds diagnosed with AIDS were African American.[59]

Latinos, who represent 8 percent of the population in the District,[60] have the second highest rate for new AIDS diagnoses both nationally and locally.[61] Furthermore, when compared to other ethnic groups, Latinos are more likely to learn of their HIV-positive status at a late stage of the disease, to delay entry into care if HIV-positive, and to lack insurance to pay for care.[62] The lack of linguistically and culturally-appropriate services and prevention messages tailored to the Latino community exacerbate these problems.[63]

WOMEN

HIV/AIDS among women of all ethnicities has been on the rise in recent years. Since 1993, the incidence of AIDS has been increasing at a faster rate among women than men in the District.[64] African-American women in particular represent the overwhelming majority of women with AIDS in the city, comprising 90 percent of women living with AIDS in the District.[65] According to the most recently available data, women in Ward 8 have the highest rate of living AIDS cases per 10,000.[66]

INCARCERATED INDIVIDUALS

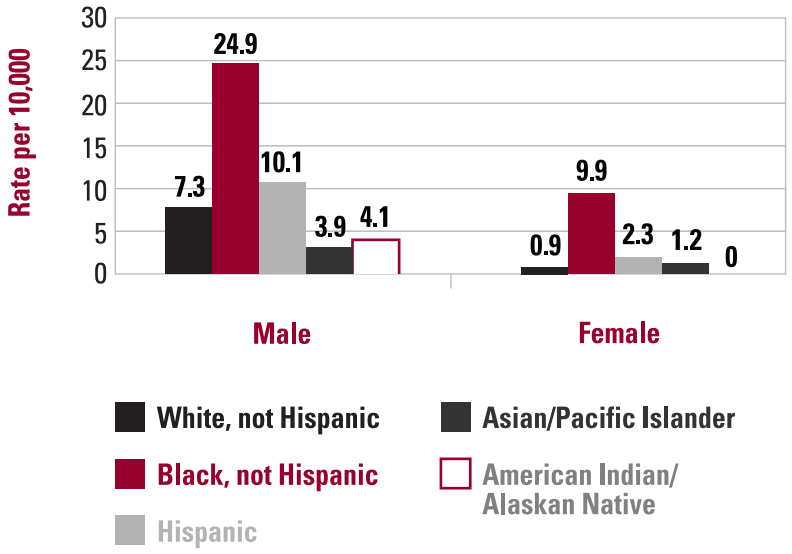
In 2001, 1.9 percent of the prison population in the United States was estimated to be HIV-positive, almost five times the HIV rate among the country's total population.[67] Inadequate data are available regarding the rate of HIV/AIDS among persons incarcerated in the District's correctional facilities.

YOUTH

In the District, there were 72 cumulative cases of AIDS among youth ages 13 to 19 years old between 1990 and 2002.[68]

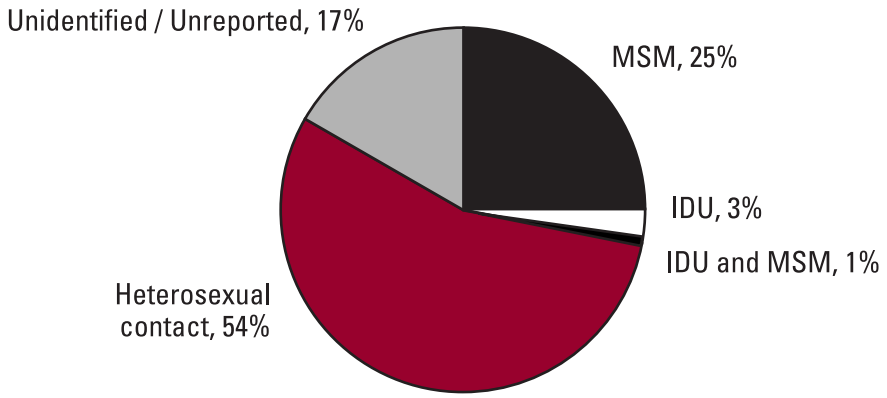
Although the number of AIDS cases among children and youth below the age of 19 has remained constant over the past five years, this may not reflect the trend of HIV transmission in this group because HIV data are not yet available in the District.[69] One

Average Annual AIDS Incidence in the District (1999-2001)



District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District of Columbia* 31 (Dec. 2003).

Modes of HIV Transmission for AIDS Cases Among 13-19 year olds in the District 1990-2002*



District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District of Columbia* 33 (Dec. 2003).

reason to believe that the AIDS incidence among 13 to 19 year olds underestimates the true rate of HIV transmission is the long lag between infection with HIV and the development of AIDS, a process that can take as long as 10 years. The rate of new AIDS cases in 20 to 24 year olds can give some clues as to the HIV transmission rate among youth, since these young people likely contracted HIV in their teenage years. Significantly, District counseling and testing data from 2003 indicate that 20 to 24 year olds have an AIDS incidence that is three and a half times greater than the incidence among 13 to 19 year olds.[70] Undoubtedly, some members of that 20 to 24 year old group were infected before they turned 20.

TRANSGENDER INDIVIDUALS

There is very little information on the transgender population in the District. What information does exist suggests that transgenders are at high risk for HIV infection. When studied, urban transgender populations have been found to have very high HIV infection rates nationwide, and represent a population at significant risk for HIV.[71] According to a survey of 252 transgender District residents in 2000, the self-reported HIV prevalence was 25 percent overall and 32 percent for male to female transgender persons.[72]

SENIOR CITIZENS

In the District, limited data are available on the trend of HIV/AIDS incidence among seniors. Counseling and testing data indicate that people over the age of 60 constitute an increasing percentage of all newly diagnosed HIV cases in recent years, accounting for less than 1 percent of newly diagnosed HIV cases in 2000, 2.4 percent in 2001, and 3.9 percent in 2002.[73] As life expectancies increase in general and those with HIV live longer due to available medications, cases of AIDS among seniors may rise. Although sexual function tends to decrease with age, recent advances in treatment for erectile dysfunction may lead to increased sexual activity among individuals over the age of 65.[74] In addition, condom use among the elderly may be less common because there is no risk of pregnancy.

CONCLUSION

HIV may be transmitted through various means. In the District, the primary modes of transmission are sexual contact and injection drug use. In order to address the modes of transmission and the needs of different populations, the involvement and coordination of various agencies is required, as discussed in the next chapter.

ENDNOTES

1 This general discussion relies heavily on the San Francisco *AIDS Foundation, AIDS 101: Guide to HIV Basics (1998), available at* http://www.sfaf.org/aids101/ (last visited July 15, 2005) [hereinafter *"HIV Basics"*].

2 National Institute of Allergy and Infectious Diseases, *HIV Infection and AIDS: An Overview,* (Mar. 2005), *available at* http://www.niaid.nih.gov/factsheets/hivinf.htm (last visited July 15, 2005) [hereinafter *"HIV Infection and AIDS"*].

3 Centers for Disease Control and Prevention, *1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults,* 41 MORBIDITY & MORTALITY WKLY. REP. RECOMMENDATIONS & REP. (Dec. 18, 1992), *available at* http://www.cdc.gov/mmwr/preview/mmwrhtml/00018871.htm (last visited July 15, 2005); *see also HIV Infection and AIDS, supra* note 2.

4 *See id.*

5 Centers for Disease Control and Prevention, *How Long Does it Take for HIV to Cause AIDS?, available at* http://www.cdc.gov/hiv/pubs/faq/faq4.htm (last visited July 15, 2005).

6 *Id.*

7 *Id.*

8 *Id.*

9 *HIV Infection and AIDS, supra* note 2.

10 Centers for Disease Control and Prevention, *Incorporating HIV Prevention into the Medical Care of Persons Living with HIV,* 52 MORBIDITY & MORTALITY WKLY. REP. RECOMMENDATIONS & REP. 9 (July 18, 2003), *available at* http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5212a1.htm (last visited July 15, 2005).

11 *Id.* at 1-2.

12 American Foundation for AIDS Research, *Basic Facts about HIV/AIDS, available at* http://www.amfar.org/cgi-bin/iowa/abouthiv/record.html?record=3 (last visited July 15, 2005).

13 Centers for Disease Control and Prevention, *HIV Prevention through Early Detection and Treatment of Other Sexually Transmitted Diseases - United States Recommendations of the Advisory Committee for HIV and STD Prevention,* 47 MORBIDITY AND MORTALITY WKLY. REP. RECOMMENDATIONS & REP. 1-24 (July 31, 1998), *available at* http://www.cdc.gov/nchstp/dstd/MMWRs/HIV_Prevention_Through_Early_Detection.htm (last visited July 25, 2005).

14 Jonathan Zenilman, *Prevention of Human Immunodeficiency Virus Transmission,* in INFECTIOUS DISEASES 1045 (Sherwood L. Gorbach, ed., 3d ed. 2003) [hereinafter *"Prevention of HIV Transmission"*].

15 *HIV Infection and AIDS, supra* note 2.

16 *Basic Facts about HIV/AIDS, supra* note 12.

17 AIDS ACTION, *What Works in HIV Prevention Among Substance Users* 1 (2001), *available at* http://www.aidsaction.org/legislation/pdf/ww4su.pdf (last visited July 15, 2005).

18 *Prevention of HIV Transmission, supra* note 14, at 1045-46.

19 *Id.* at 1046.

20 *Id.*

21 *HIV Infection and AIDS, supra* note 2; INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, REDUCING THE ODDS: PREVENTING PERINATAL TRANSMISSION OF HIV IN THE UNITED STATES 45 (Michael A. Stoto et al., eds., National Academy Press 1999), *available at* http://www.nap.edu/books/0309062861/html/index.html (last visited July 15, 2005).

22 Press Release, National Institutes of Health, Mother to Infant HIV Transmission Rate Less Than 2% in Phase III Perinatal Trial (Feb. 8, 2001), *available at* http://aidsinfo.nih.gov/aprs/ (last visited July 15, 2005); Hoosen Coovadia, Antiretroviral Agents – *How Best to Protect Infants from HIV and Save Their Mothers from AIDS*, 351 NEW ENG. J. MED. 289-92 (July 15, 2004), *available at* http://content.nejm.org/content/vol351/issue3/index.shtml (last visited July 15, 2005).

23 Jesse L. Goodman, *The Safety and Availability of Blood and Tissues – Progress and Challenges,* 351 NEW ENG. J. MED. 819-22 (Aug. 19, 2004), *available at* http://content.nejm.org/content/vol351/issue8/index.shtml (last visited July 15, 2005).

24 *HIV Infection and AIDS, supra* note 2.

25 *Basic Facts about HIV/AIDS, supra* note 12.

26 Centers for Disease Control and Prevention, *Basic Statistics* (last revised June 20, 2005), *available at* http://www.cdc.gov/hiv/stats.htm (last visited July 15, 2005).

27 *Id.*

28 *Id.* (citing M. Glynn and P. Rhodes, *Estimated HIV Prevalence in the U.S. at the End of 2003,* National HIV Prevention Conference (June 2005), Abstract 595).

29 Centers for Disease Control and Prevention, *Cases of HIV Infection and AIDS in the United States,* 2003, 15 HIV/AIDS SURVEILLANCE REPORT, (2004), *available at* http://www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf (last visited July 18, 2005).

30 Centers for Disease Control and Prevention, *CDC Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome*, MORBIDITY & MORTALITY WKLY. REP. RECOMMENDATIONS & REP. 1 (Dec. 10, 1999), *available at* http://www.cdc.gov/mmwr/PDF/rr/rr4813.pdf (last visited July 18, 2005) [hereinafter *"CDC Guidelines for National HIV Case Surveillance"*].

31 *HIV/AIDS Surveillance Report, supra* note 29, at 27.

32 District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District of Columbia* 1 (Dec. 2003) [hereinafter *"2003 Epi Profile"*], *available at* http://www.doh.dc.gov/doh/frames.asp?doc=/doh/lib/doh/services/administration_offices/hiv_aids/pdf/epi_profile_2004.pdf (last visited July 23, 2005).

33 *Id.*

34 District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District of Columbia, December 2003: Supplemental Report* 29 (Mar. 4, 2005), *available at* http://www.doh.dc.gov/doh/frames.asp?doc=/doh/lib/doh/services/administration_offices/hiv_aids/pdf/EpiProfileSupplementFinal061505.pdf (last visited July 23, 2005) [hereinafter *"2005 Epi Supplement"*].

35 *Id.*

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PART 1: CHAPTER II

GOVERNMENT STRUCTURE

CHAPTER INFORMATION:

This chapter presents an overview of the federal and District government agencies and programs that furnish prevention and care services for HIV/AIDS in the District. Several federal agencies provide funding to the District for the provision of prevention and care services for individuals with HIV/AIDS. On a local level, HAA has primary responsibility for addressing the HIV/AIDS epidemic. Although this report does not recommend changing the District's government structure for HIV/AIDS services, subsequent chapters contain recommendations for improving coordination among existing agencies.

THE FEDERAL GOVERNMENT

Several agencies within the federal government play significant roles in providing HIV/AIDS care and prevention in the District. These federal agencies provide the vast majority of funding for local governments and service providers. They also conduct nation-wide epidemiological monitoring of public health, coordinate national prevention and care efforts, and oversee how local governments use funds.

The primary federal agencies addressing HIV/AIDS are:

- **The Health Resources and Services Administration (HRSA)**, through its HIV/AIDS Bureau (HAB), administers all programs funded under the Ryan White Comprehensive AIDS Resources Emergency Act (Ryan White). Ryan White provides funds to improve the quality and availability of care for people with HIV/AIDS and their families.
- **The Centers for Disease Control and Prevention (CDC)** coordinates and leads efforts in disease prevention and control, health promotion, and education. Through its National Center for HIV, STD, and TB Prevention, the CDC funds HIV/AIDS prevention grants, supplies local health departments with comprehensive HIV prevention programs, and coordinates and conducts surveillance on HIV/AIDS.
- **The Substance Abuse and Mental Health Services Administration (SAMHSA)**, through its HIV/AIDS & Hepatitis Program Area, increases access to prevention and treatment services for individuals with or at risk of HIV/AIDS due to substance abuse and mental health disorders. SAMHSA places a particular emphasis on people of color disproportionately affected by the HIV/AIDS epidemic.
- **The Centers for Medicare & Medicaid Services (CMS)** works in partnership with the states to administer Medicaid. Nationally, Medicaid is the primary source of health insurance coverage for low-income beneficiaries living with HIV/AIDS.
- **The Housing Opportunities for Persons with AIDS (HOPWA)** office of the Department of Housing and Urban Development (HUD) provides housing assistance and related supportive services for low-income persons with HIV/AIDS and their families.

THE DISTRICT OF COLUMBIA GOVERNMENT

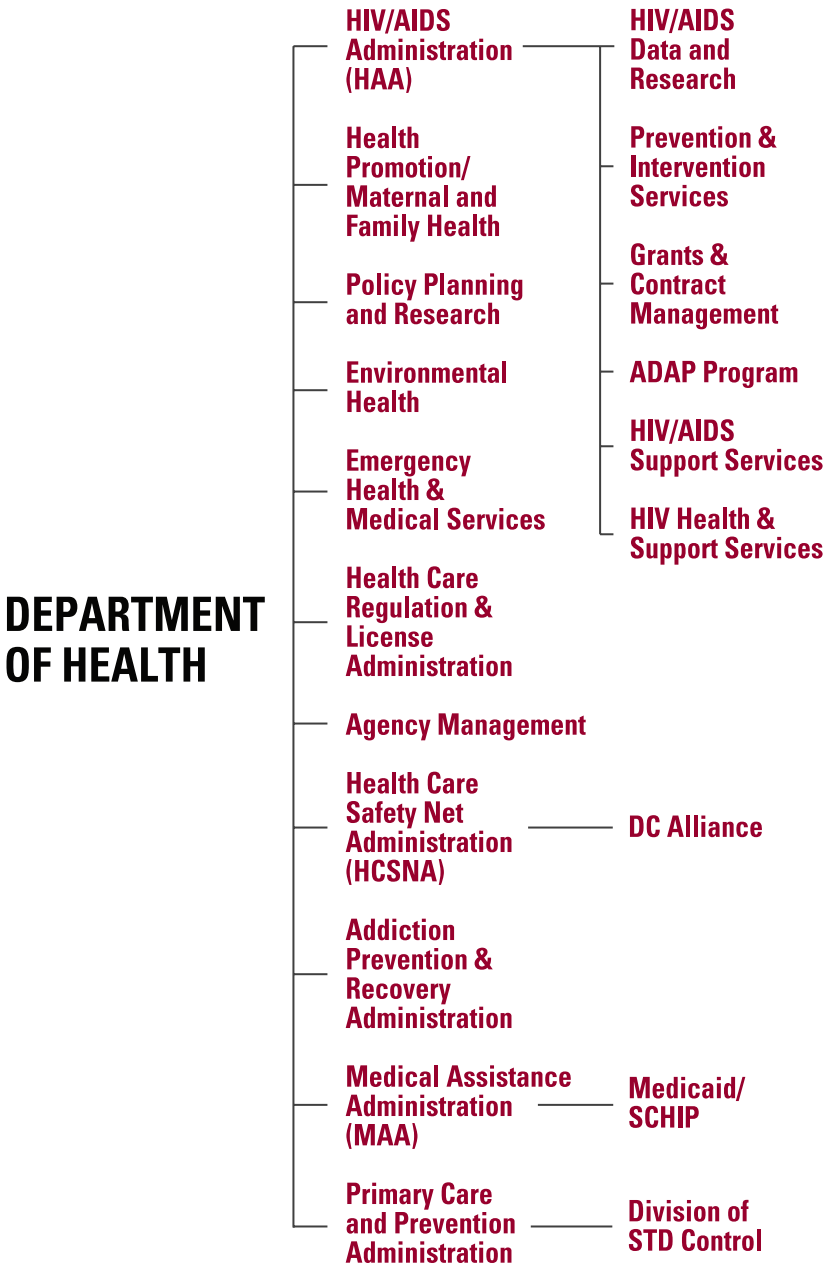
The DOH is responsible for coordinating health care services for the District's residents. Within the DOH, HAA focuses specifically on HIV; however, several other DOH offices and District agencies play important roles in addressing the epidemic.

DEPARTMENT OF HEALTH

The figure below shows the current structure of the DOH, reflecting its reorganization in late 2004. As a result of this reorganization, the Administrator of HAA now reports directly to the Director of the DOH.

HIV/AIDS ADMINISTRATION

HAA is responsible for funding and overseeing HIV/AIDS prevention and care services for District residents. These services are provided primarily through partnerships with health and community-based



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organizations. Services include medical support, HIV counseling and testing, collection and analysis of data, and the provision of education, information, referrals, and intervention services. HAA's mission is to decrease the incidence of HIV/AIDS and the number of deaths related to HIV/AIDS in the District through surveillance, tracking, monitoring, and intervention.

OTHER RELEVANT OFFICES WITHIN THE DOH

As the agency responsible for coordinating the District's response to HIV/AIDS, HAA should have relationships with other offices within the DOH that serve populations with a high incidence of HIV/AIDS:

- **The Addiction Prevention and Recovery Administration (APRA)** focuses on the prevention and treatment of substance abuse in the District. APRA provides oversight, sets standards, and monitors the quality of substance abuse treatment services delivered. APRA's Office of Special Population Services provides case management, prevention education and outreach, and specialized treatment services for those living with HIV/AIDS.[76]
- **The Division of STD Control and Prevention (STD Division)** aims to curb the spread of STDs within the District, through clinical treatment services and ongoing education and outreach with District residents and providers. The STD Division is responsible for providing STD testing and treatment, counseling and training, and surveillance of STD infection in the District. The Division also operates the District's STD Clinic.
- **The Health Care Safety Net Administration (HCSNA)** oversees the Alliance, a partnership with private health care providers in the District, to finance health care for certain uninsured District residents.
- **The Medical Assistance Administration (MAA)**, the Medicaid agency for the District, administers health care financing for eligible uninsured persons within the District.
- **The Maternal and Child Health Administration** addresses natal care and the prevention of perinatal transmission of HIV.

OTHER RELEVANT DISTRICT AGENCIES

Besides the DOH, other departments within the District government provide services to at-risk populations:

- **The Department of Mental Health (DMH)** coordinates the District's mental health system and provides community mental health services and in-patient services at St. Elizabeths Hospital. Many individuals with mental illnesses are also living with HIV/AIDS.
- **The Department of Corrections (DOC)** houses a population with a high incidence of HIV/AIDS. Through private contractors funded by HAA and the DOC, some inmates receive HIV prevention education, testing and counseling, treatment, and discharge planning services.
- **District of Columbia Public Schools (DCPS)** is responsible for District youths' education, including health education related to HIV/AIDS.
- **The Income Maintenance Administration (IMA)** administers the District's welfare program, which provides eligible District residents with services such as cash assistance, Medicaid, and food stamps. Many HIV-positive individuals depend on these public programs.
- **The Office of Gay, Lesbian, Bisexual, and Transgender (GLBT) Affairs** serves as a liaison to the Executive Office of the Mayor and other District agencies that provide services and community outreach to GLBT constituents. The Office has established the Mayor's GLBT Executive Advisory Committee and sub-committees to define issues of concern to the GLBT community and find innovative ways of utilizing government resources to help address pertinent issues.

COMMITTEES

Both through federal mandate and local initiative, the District has established a number of entities to address HIV/AIDS issues:

- **The Mayor's Advisory Committee on HIV/AIDS** was created to advise the Mayor, DOH, and HAA on the development, implementation, and evaluation of HIV/AIDS policies in the District. The Committee reviews existing and proposed HIV/AIDS policy, develops HIV/AIDS policy position papers, coordinates functions among other advisory committees, and provides a forum for District residents to voice concerns about existing and proposed HIV/AIDS policy. It is composed of persons either living with or affected by HIV/AIDS, as well as service providers, academics, and government officials.
- **The D.C. Council Committee on Health**, which was created in 2005, has jurisdiction over the DOH and health-related issues in the District. The committee is chaired by D.C. Councilmember David Catania and includes Councilmembers Jack Evans, Jim Graham, Vincent C. Gray, and Vincent B. Orange, Sr.[77]
- **The HIV/AIDS Prevention Community Planning Group (CPG)** is required for the District to receive prevention funding from the CDC. The District's CPG is comprised of affected populations, epidemiologists, scientists, providers, and public health department staff. The CPG drafts a prevention plan that identifies priority target populations and interventions for each identified target population.[78] This plan is developed from epidemiologic data and an assessment of prevention needs.
- **The Ryan White Planning Council**, as required by the federal government, meets regularly to set funding priorities for allocating resources for the provision of HIV/AIDS services and to develop a plan for the organization and delivery of care services. The Planning Council is comprised of representatives from a number of groups affected by HIV/AIDS including, but not limited to: people living with AIDS, the recently incarcerated, women, MSM, and the organizations that serve these populations.

CONCLUSION

Several federal and District agencies are responsible for the provision of HIV/AIDS prevention and care services locally. Given the number of entities involved, strong coordination and leadership are essential, especially for the effective care of individuals living with HIV/AIDS who may struggle with multiple needs. Subsequent chapters contain specific recommendations for improving coordination among the relevant agencies.

ENDNOTES

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PART 2

FINDINGS AND RECOMMENDATIONS CONCERNING THE DISTRICT'S RESPONSE TO THE HIV/AIDS EPIDEMIC

PART 2: CHAPTER III

HIV AND AIDS SURVEILLANCE

CHAPTER INFORMATION:

HIV/AIDS surveillance is the means by which government public health agencies track the impact of HIV and AIDS. Positive HIV test results and AIDS diagnoses are aggregated and analyzed to generate local and national surveillance data. Surveillance data are then used to make determinations about how to allocate funding, both on a local and federal level, and to formulate effective treatment and prevention strategies. As will be discussed further below, the collection and analysis of *HIV infection* data are critical to assessing the current state of the epidemic and developing an effective and targeted response.

This chapter provides background information on HIV and AIDS surveillance in the District. It then explains the importance of surveillance data and analysis, and identifies current deficiencies in the District's system for collecting, analyzing, and effectively disseminating timely surveillance data. This chapter then recommends steps for ensuring adequate staffing of HAA's Surveillance Division, increasing data dissemination (including HIV data), enforcing existing HIV/AIDS reporting requirements, and improving data storage and protection.

BACKGROUND

GOALS AND PURPOSES OF SURVEILLANCE

HIV/AIDS surveillance efforts involve the aggregation of HIV testing results and reports of AIDS diagnoses. Surveillance tracks the spread of HIV infection and AIDS geographically, demographically, and by other categories such as risk factors – *i.e.,* characteristics or behaviors that place an individual at high risk for HIV infection. The analysis of HIV and AIDS data is critical to understanding modes of transmission and other characteristics of the HIV/AIDS epidemic. An understanding of the number of individuals living with HIV/AIDS and modes of HIV transmission allows for a better allocation of funding and more appropriate planning of care and treatment services.

In the District, HAA is responsible for conducting HIV and AIDS surveillance through its Surveillance Division. Primarily funded by the CDC, Surveillance Division staff investigates potential HIV and AIDS cases and their modes of transmission, analyze data, prepare epidemiologic statistical reports and data presentations, and respond to requests for information. Collaborating with other divisions within DOH, HAA, and community planning groups, the Surveillance Division prepares the epidemiologic data reports required to receive federal funding for HIV prevention and care programs.

HIV SURVEILLANCE

Since the 1980s, public health agencies have been conducting AIDS surveillance to monitor the impact of the HIV/AIDS epidemic. According to the CDC, prior to the advent of effective therapy for HIV/AIDS in 1996, AIDS surveillance data "reliably detected changing patterns of HIV transmission and reflected the effect of HIV prevention programs on the incidence of HIV infection and related illnesses in specific populations."[79] After 1996, however, HIV/AIDS medication slowed the progression of HIV to AIDS, so that AIDS surveillance no longer reliably reflected trends in HIV transmission.[80] AIDS surveillance, therefore, could not accurately inform the need for prevention and care services because AIDS data fail to account for the significant number of people who have HIV but have not yet developed AIDS.[81] Hence, AIDS surveillance alone can no longer provide a complete picture of the epidemic.

Following the development of antiretroviral therapy in 1996, the CDC recommended in 1997 that all public health agencies conduct surveillance of HIV infections in addition to AIDS surveillance.[82] HIV surveillance has a number of important benefits compared to AIDS surveillance. First, HIV data provide a more complete reflection of the numbers of people infected with the virus at the present time than AIDS data alone. Second, HIV surveillance provides more current information regarding trends in modes of transmission within subpopulations than that offered by AIDS surveillance.

The District has conducted AIDS surveillance since the early stages of the epidemic. Physicians and laboratories report AIDS cases to DOH and identify each case by the patient's name and address.[83] In 1999, the District began to develop a process for HIV reporting. Although the District had been conducting name-based AIDS surveillance for many years, some District residents opposed such surveillance. According to Marlene N. Kelley, M.D., the Interim Director of DOH at the time, the opposition was due to "historical experiences of discrimination and fear of losing confidentiality about one's HIV status."[84] Dr. Kelley said that some people in the District believed that name-based surveillance would deter people in certain high-risk populations from getting tested for HIV.[85]

Community debate concerning whether to conduct HIV surveillance by name or by coded unique identifier (UI) lasted several years. District officials implemented HIV reporting by coded UI in January 2001, when HIV became a reportable disease in the District.[86] The District's UI is a combination of letters and numbers derived from portions of the person's last name and social security number, as well as his or her date of birth and sex.

By the time HAA received the first HIV case reports in December 2001, many jurisdictions had already been collecting HIV infection case information for several years.[87] In fact, the CDC reported that as of November 1, 1999 – approximately one year after CDC had issued guidance for HIV surveillance – 34 states had implemented HIV surveillance using name-based reporting, whereas four states were using a coded UI system for HIV surveillance.[88] As part of their comprehensive HIV/AIDS surveillance programs, numerous states have been conducting HIV surveillance since 1985.[89]

HAA currently collects HIV case reports, which include risk behavior information, so that trends in mode of transmission can be identified among subpopulations.[90] However, HAA has yet to release data concerning the District's HIV incidence and prevalence and trends in mode of transmission among subpopulations. According to Dr. Matthew McKenna, Chief of HIV Incidence and Surveillance at the CDC, the CDC does not have any standards regarding the maturation time for data in HIV surveillance systems using coded UIs.[91] However, Dr. McKenna says it takes about two years to have quality data in any reporting system and four to five years to have data that are useful for trend analysis.[92] Supporting this position, the Institute of Medicine of the National Academies reports, "Case reporting systems for new diseases take time to mature and become fully operational. For a system to operate well, physicians and other practitioners need to be educated about the need for new requirements for disease reporting. The burden of new reporting obligations can be increased by complex data requirements, such as the creation of encryption codes for patients in states with code-based reporting."[93]

DATA DISSEMINATION

HAA disseminates AIDS surveillance data and analysis through data presentations, fact sheets, responses to individual data requests, and the Epidemiologic Profile (Epi Profile). The Epi Profile is a required component of the HIV Prevention Plan, which the District should submit to the CDC as part of its application for funding for HIV prevention activities.

The Epi Profile typically includes summaries of AIDS incidence, prevalence, rates, and trends. The Epi Profile presents AIDS data by gender, race or ethnicity, age, mode of transmission, and geographic area. Data on AIDS and comorbidities, such as STDs, are also provided.

The Epi Profile is used to prepare the District's Prevention Plan every other year. The CDC requires HAA and the HIV/AIDS

Community Planning Group (CPG) to work collaboratively to prepare the Prevention Plan in order to apply for CDC funding for prevention interventions, which are further discussed in Chapter IV. HAA is responsible for providing guidance to the CPG, developing the Epi Profile, and conducting an assessment of services available in the community.[94] The CDC's guidance indicates that the Epi Profile and the community services assessment should be discussed and agreed upon by both the health department and the CPG in order to facilitate the efficiency and effectiveness of the prevention planning process.[95] The CPG reviews and uses key data (including the Epi Profile and the community services assessment) to establish priorities for prevention activities in the community.[96]

Epidemiologic Profile:

A document that describes the HIV/AIDS epidemic within various populations and identifies characteristics of both HIV-positive and HIV-negative persons in defined geographic areas. It is composed of information gathered to describe the effect of HIV/AIDS on an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics. The epidemiologic profile serves as the scientific basis for the identification and prioritization of HIV prevention and care needs in any given jurisdiction.

Centers for Disease Control and Prevention, *HIV Prevention Community Planning Guide* 20 (2003).

HIV/AIDS REPORTING REQUIREMENTS

In the District, physicians and laboratories are required by law to report a diagnosis of HIV or AIDS to HAA within 48 hours of diagnosis.[97] These reporting requirements can be enforced through civil fines or penalties.[98] Furthermore, a physician licensed by the District may lose his or her license to practice medicine if he or she willfully fails to make the required reports.[99]

DATA STORAGE AND PROTECTION

The CDC's Guidelines for HIV/AIDS Surveillance call for protections and security measures to uphold the integrity and confidentiality of the surveillance system, information, and records.[100] These requirements include the use of physical barriers, electronic protections, and standard operational procedures such as limiting access to authorized personnel, shredding of documents, password-protecting and encrypting data, and maintaining all HIV/AIDS surveillance reports and data in a physically secure location and confidential manner at all times.[101] Information security policies also should incorporate provisions for the removal of personally identifying information and encryption before electronically transferring AIDS case data to the CDC.[102]

FINDINGS AND RECOMMENDATIONS

The District's HIV/AIDS surveillance program needs significant improvements. Additional staff is needed to investigate, collect, review, enter, manage, analyze, interpret, and evaluate HIV/AIDS epidemiologic and behavioral data. In addition, improved dissemination of surveillance data is critical. While the Surveillance Division provides AIDS data and formula-based estimates of HIV incidence to the CPG and the Ryan White Planning Council, the Surveillance Division has not disseminated the District's HIV surveillance data and has no immediate plans to do so.

LEADERSHIP AND RESOURCES OF THE SURVEILLANCE AND EPIDEMIOLOGY DIVISION

HAA's Surveillance Division has a significant number of personnel vacancies and is currently headed by its second consecutive interim director.[103] Of the Surveillance Division's 10 staff members, there is only one staff assistant.[104] As a result, the Surveillance Division has been unable to provide timely input of data.[105] The vacancy rate of over 50 percent has had a significant impact on the Surveillance Division's ability to fulfill its objectives and on the morale of the Surveillance Division's staff.[106]

There are currently 13 vacant positions in the Surveillance Division, many of which have been vacant for over one year.[107] The District has received federal funding for these positions; thus, there would be minimal, if any, costs to the District to fill

these positions. Despite the available funding, it appears that insufficient effort currently is invested in advertising and filling these vacancies.[108] For example, eight of these positions were not posted on the District's Office of Personnel website until May 2005, and it does not appear that the other five positions have ever been advertised.[109] HAA staff reports that they made a request to the CDC in early fall of 2004 for seven CDC staff to be detailed to the Surveillance Division.[110] HAA staff also reports, however, that they are unaware of the CDC ever providing a large number of full-time staff to a local public health agency,[111] and thus it seems unlikely that CDC will provide the necessary staff. The failure to fill these positions prevents the Surveillance Division from performing its duties and results in the District's need to reprogram federal funds.[112] The DOH and HAA Directors should make the leadership and staffing of the Surveillance Division a top priority.

The vacancies in the Surveillance Division were raised in a recent hearing before the D.C. Council's Committee on Health.[113] At the hearing, HAA indicated that the hiring process and bureaucracy at HAA, DOH, and the Office of Personnel had impeded attempts to fill these vacancies.[114] In order to facilitate the hiring of new staff, Chairman David Catania offered to introduce an emergency measure granting HAA temporary hiring authority to bypass the Office of Personnel and attempt to fill the positions on its own.[115] In a CPG meeting on July 22, 2005, HAA staff reported that direct hiring authority would be welcomed and that HAA is currently discussing the possibility with the Deputy Mayor's office.[116] It is critical that the staffing vacancies in the Surveillance Division are filled, and HAA should pursue every possible means of addressing its personnel shortages.

HIV SURVEILLANCE

Accurate and complete HIV surveillance data are essential to plan HIV prevention programs and allocate healthcare resources. Although HAA has collected HIV data for the past three and a half years, it has not yet publicly disseminated a report on HIV data. During a recent public hearing before the D.C. Council Committee on Health, HAA officials stated that to ensure the inclusion of prevalent HIV cases and unbiased data, HIV data should not be released until the agency has accumulated five years of data.[117] Based on surveillance best practices, it takes about two years for an HIV surveillance program to gather mature data and two or three more years before trends in the data can be interpreted.[118] Mature data may be released with appropriate caveats, even before trend analysis can be completed.[119] HAA should therefore disseminate the District's HIV data with the necessary caveats in order to provide information about HIV transmission during particular time periods. If vacancies in the Surveillance Division are filled, HAA should have sufficient staffing resources to disseminate HIV data promptly.

In order for HAA to be able to conduct trend analysis of the District's HIV data, the HIV data must be complete. HAA's Counseling, Testing, and Referral (CTR) program data on individuals tested for HIV at publicly-funded sites or events can be used to gain insight on HIV prevalence and incidence. But these data are for a limited cross-section of the District's population and cannot be used to determine the District's HIV prevalence and incidence. For HAA's HIV data to be complete and representative of the District's population, the CTR data must be supplemented by HIV case reports from private medical offices and laboratories. HAA should therefore ensure that physicians and laboratories report all HIV cases in a timely manner, as further discussed below.

In addition, HAA needs to complete an evaluation of its HIV surveillance system prior to publishing information on trends in HIV data. HAA reports that it is not equipped to conduct the necessary in-depth process of evaluating the proficiency of its UI code, the efficiency of the UI database system, and the timeliness of case reporting. The UI system needs evaluation for several reasons, including the large number of duplicate or incomplete HIV case reports. HAA staff reports that for every 26 HIV case reports, there is only one new unduplicated and complete HIV case. Given the understaffing of the Epidemiology and Surveillance Division, HAA should contract with an outside expert to evaluate the HIV surveillance system. HAA may be able to

obtain additional funding from the CDC to hire this outside expert. In the alternative, HAA should explore the possibility of partnering with a local university or research organization to conduct the evaluation at a reduced rate or on a volunteer basis.

HAA staff indicates that the release of HIV data may be further delayed if the District changes its UI. Specifically, legislation pending before the D.C. Council would amend the District's HIV reporting requirements by prohibiting the use of social security numbers and country of origin as part of the HIV case report.[120] The CDC's Dr. McKenna confirms that, based on the experience of other jurisdictions, altering the District's UI would likely be a significant setback in terms of the ability of the Surveillance Division to analyze and disseminate HIV data promptly.[121]

The central problem remains that current staff vacancies preclude HAA from completing the necessary collection, analysis, evaluation, and dissemination of HIV data. District decision makers should realize that until these staffing resources are provided, it is unlikely that critical HIV surveillance data will be disseminated.

DATA DISSEMINATION

Data dissemination is indispensable for the optimal allocation of prevention and care services. For example, the District's CPG relies on the Epi Profile to prioritize prevention activities in the District. During the community planning process for the 2005-2006 CDC-mandated Prevention Plan, the CPG experienced difficulty obtaining the necessary epidemiologic data.

The 2003 Epi Profile was distributed in December 2003. In April 2004, the CPG communicated its concerns about deficiencies in the 2003 Epi Profile to HAA. HAA, in consultation with CPG members, produced a Supplemental Report to the 2003 Epi Profile, which was approved by the vote of a quorum of CPG members in April 2005.

HAA's failure to present comprehensive data to the CPG in a timely manner contributed to the delay in the development of the 2005-2006 HIV Prevention Plan. The 2005-2006 HIV Prevention Plan was due in December 2004; however, due to HAA's failure to provide necessary epidemiological data and other information, the Plan was not ready as of July 2005.[122] In a June 29, 2005 letter to the CDC, the CPG requested the CDC's assistance in moving the prevention planning process forward.[123]

It is critical that the Prevention Plan be based on accurate and complete epidemiological data and that the CPG receives all required documents from HAA. That is not now the case. Epidemiological data provide the primary basis for the development of the Prevention Plan. The Prevention Plan plays a significant role in the CDC's determination of the District's prevention funding levels. Given the importance of the Prevention Plan, the Surveillance Division should devote necessary resources to preparing the Epi Profile and responding to data requests from the CPG. Various CPG members have publicly stated that collaboration between HAA and the CPG generally, and between the Surveillance Division and the CPG in particular, has been lacking. In part, the ineffective collaboration may stem from the overextended and understaffed Surveillance Division. In order to provide effective and timely support to the CPG's prevention planning process, HAA must obtain sufficient staffing in the Surveillance Division and should make an institutional commitment to improved communication and collaboration both within the agency and with the CPG.

In order to strengthen the prevention planning process in the District, HAA and the CPG should also consult with the Behavioral and Social Science Volunteer Program (BSSV) of the American Psychological Association, Office on AIDS. The BSSV, a national HIV prevention technical assistance program funded by the CDC, has a network of behavioral and social science volunteers to offer free and ongoing technical assistance to assist with HIV prevention planning efforts.[124]

In addition to the CPG, the Ryan White Planning Council relies on the epidemiological data compiled by HAA in order to allocate federal funding for HIV/AIDS services. Like the CPG, the Ryan White Planning Council has experienced difficulties in obtaining data from HAA.

HAA should publicly disseminate data in more frequent reports. The only epidemiological information on HAA's

website is the 2003 Epi Profile and the related 2005 supplement. In addition to the required Epi Profile, HAA should disseminate other data on a regular basis. Cities including New York, San Francisco, and Baltimore publish quarterly reports on HIV and/or AIDS surveillance data on their websites.[125] Some county and state health departments, including those of Illinois, California, Massachusetts, and Seattle/King County, provide monthly surveillance reports on their websites.[126] The CDC recommends regular publication of such data for the use of health agencies, community planning groups, academia, providers, and the public.[127] In addition, Philadelphia, Baltimore, New York, San Francisco, and Los Angeles make de-identified, unanalyzed HIV and AIDS data publicly available for independent analysis. In sum, to ensure access to accurate and timely information on the local HIV/AIDS epidemic, HAA should publish surveillance data and reports regularly on its website. Additional recommendations about the content of HAA's website are discussed in Appendix C.

HIV/AIDS REPORTING REQUIREMENTS – EDUCATION AND ENFORCEMENT

HAA officials expressed concern about the timeliness and completeness of HIV/AIDS case reporting by doctors and laboratories.[128] HAA officials cite discrepancies in reported data versus the data that are discovered when the Surveillance Division staff visits private doctors' offices to survey medical records, a process called "active surveillance." The CDC recommends that, to ensure that all data are accurate and complete, active surveillance should be done routinely *in addition* to passive surveillance (the receipt of HIV/AIDS case report from doctors' offices and laboratories).[129] Furthermore, CDC guidelines advise that all surveillance programs should conduct regular, ongoing assessments of their surveillance and reporting systems.[130]

To date, HAA has undertaken only one small study to assess the reporting by private physicians. Several years ago, to assess private doctors' understanding of and compliance with the reporting requirements, HAA conducted a survey of 11 doctors. The survey indicated that at least one doctor did not understand the reporting regulations and that some were concerned both about the time required to make these reports as well as patient privacy.[131] In a related study to assess the completeness of the HIV/AIDS case reports submitted by seven private doctors between 1996 and 1998, HAA concluded that private doctors significantly underreport HIV/AIDS diagnoses.[132] Although the study was based on a small sample, HAA officials have pointed to the results as evidence that HIV/AIDS cases may be underreported. The extent to which data are being incompletely or inaccurately reported is unknown, but other jurisdictions, including California, have identified serious problems with underreporting and reporting delays by private physicians.[133] An additional study will be necessary to provide an accurate picture of underreporting by private doctors; the study should also include reporting by laboratories to fully capture the reporting situation in the District. HAA should consider seeking additional funding to complete the reporting study.

There are inexpensive methods that could be utilized to heighten physicians' understanding of the importance of the reporting regulations and improve their compliance with those regulations. When the HIV reporting requirement became effective in 2001, HAA conducted a multi-pronged campaign to publicize the new reporting requirement to both the general public and the medical community. Among other efforts, HAA created a website, http://www.hivcounts.net, to provide information about the HIV/AIDS reporting regulations, including the forms for the required case reports. Such efforts should be strengthened and conducted on an ongoing basis. For example, the D.C. Board of Medicine, which is responsible for regulating doctors practicing in the District, maintains a website[134] and periodically publishes a newsletter for District-licensed physicians.[135] Both the website and newsletter should be used to publicize the importance of the reporting requirements. Similarly, the Medical Society of the District of Columbia, a private organization, maintains a website and publishes a monthly newsletter for its physician members.[136] The Medical Society publishes on its website reporting

requirements related to other STDs.[137] HAA could request that HIV/AIDS reporting requirements also be published on the Medical Society website and, at virtually no cost, communicate these reporting requirements to the several thousand members of the Medical Society. HAA should undertake this and other simple and inexpensive methods of communication.

Although HAA attributes its data problems at least in part to physician and laboratory noncompliance with reporting requirements, no enforcement action has ever been brought against a physician or laboratory. To the extent that HAA identifies unreported cases, enforcement action should be taken. It is likely that consistent enforcement of the law would increase the timely reporting by private medical offices and laboratories. In order to enforce the reporting requirements, HAA staff should notify the DOH General Counsel of any suspected violations. After an investigation, the DOH General Counsel may refer substantiated violations to the Attorney General for enforcement action. The DOH General Counsel's office reports that it has not been informed of any violations. HAA should not simply accept failures by doctors and laboratories to report HIV and AIDS cases without referring such failures to the Attorney General for enforcement action. To the extent that the referral mechanism is perceived as cumbersome or ineffective, legislative action may be necessary to enable HAA or DOH staff to warn and fine physicians and laboratories in order to ensure prompt and complete reporting.

DATA STORAGE AND PROTECTION

HAA uses separate databases for HIV and AIDS data, which creates unnecessary work. For each new HIV or AIDS case report, staff must check each database for possible duplicate records. If a case report includes both an HIV and an AIDS diagnosis, the data must be entered twice. Furthermore, two databases complicate data analysis. For these reasons, HAA should combine HIV and AIDS data into a single database, with the assistance of qualified information technology consultants. As with the evaluation of the HIV surveillance system, HAA should explore the possibility of seeking assistance from a local university, another organization, or the CDC to integrate the HIV and AIDS databases.

Another problem with HAA's databases is that HAA does not maintain secure back-up files of surveillance data.[138] In the event of a fire, flooding, or other disaster at HAA's headquarters, the surveillance data could be lost. HAA would then be at risk for losing funding, and both HAA and the District's CBOs would be unable to plan their priorities and activities based on up-to-date, accurate information. The current back-up is insufficient in that: (1) the back-up relies on data from the District's regular reports to CDC, which do not include all data elements collected, and (2) the data collected between submission of reports to the CDC would be lost. HAA should ensure that all of its data are regularly backed up at a remote secure location. Off-site storage is considered to be the best practice in the medical community.[139] For example, the California Health & Safety Code mandates that all medical records stored on an electronic medium must also have an off-site back-up storage system.[140] If the District uses storage space in an existing District office building, the cost associated with off-site data back-up should be minimal.

SUMMARY OF RECOMMENDATIONS

Leadership and Staffing Resources. DOH and HAA should move quickly to ensure adequate staffing of the Surveillance Division and utilize existing CDC funding fully by filling the 13 vacant positions in the Surveillance Division. If hiring qualified personnel cannot be achieved quickly, HAA should explore mechanisms such as contracting with outside entities to staff critical surveillance functions. As a priority, HAA should make every effort to hire immediately a qualified, experienced epidemiologist with proven management ability and familiarity with HIV/AIDS surveillance to head this critical department.

HIV Data Analysis and HIV/AIDS Data Dissemination. To enhance and direct District planning and policy making, HAA

should make HIV data available immediately with appropriate caveats. HAA should also contract with an expert to evaluate the HIV surveillance system. Both HIV and AIDS data should be analyzed and reported on a quarterly basis. In preparing the quarterly reports, HAA should present data in a user-friendly format. Both reports and data sets should be made available on the HAA website. HAA should also evaluate its processes for supporting the planning roles of the CPG and the Ryan White Planning Council and develop a workable method for providing timely, accurate epidemiologic data to both groups. In addition, HAA should make available de-identified data sets to enhance transparency and facilitate outside analysis of the data. Additional recommendations about the content of HAA's website are discussed in Appendix C.

HIV/AIDS Reporting Requirements. The District, through the Attorney General, should enforce existing HIV/AIDS reporting requirements by levying fines on physicians and laboratories that fail to report cases of HIV or AIDS. To improve compliance, HAA should renew its efforts to publicize the HIV/AIDS reporting requirements to private doctors, other providers, and laboratories. The Board of Medicine and the Medical Society of the District of Columbia each appear to offer effective vehicles to promote compliance at little cost. In order to evaluate reporting and ensure accountability, HAA should conduct an in-depth study of reporting by private doctors and laboratories.

Data Storage and Protection. HAA should combine its HIV and AIDS databases into a single database system, and should take steps to ensure that surveillance data are backed up at a remote data storage site.

CONCLUSION

Remedying current deficiencies in the analysis and dissemination of surveillance data should be a priority in the District. These data significantly impact the deployment of prevention efforts and the allocation of adequate care resources for persons living with HIV/AIDS. Leadership and staffing should be improved in order to ensure the proper analysis and dissemination of data. In addition, coordination with responsible enforcement agencies will improve accountability of providers and labs and ensure collection of relevant data.

ENDNOTES

79 *CDC Guidelines for National HIV Case Surveillance, supra* note 30, at 3.

80 *Id.*

81 *Id.*

82 *Id.*

83 22 D.C. Mun. Regs. §§ 206.2-.3 (2005).

84 Letter from Marlene N. Kelley, Interim Director, District of Columbia Department of Health, to Phil Mendelson, Councilmember (At Large), Council of the District of Columbia (Apr. 12, 1999), *available at* http://www.glaa.org/archive/1999/nameskelley0412.shtml#kelley (last visited July 22, 2005).

85 *Id.*

86 22 D.C. Mun. Regs. §§ 206 (2005).

87 *CDC Guidelines for National HIV Case Surveillance, supra* note 30, at 3.

88 *Id.*

89 *Id.*

90 Interview with District of Columbia government officials.

91 Telephone Interview with Dr. Matthew T. McKenna, Chief, HIV Incidence and Surveillance Branch, Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention (July 1, 2005) [hereinafter "July 1 Telephone Interview with Dr. Matthew T. McKenna"].

92 *Id.*

93 INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, MEASURING WHAT MATTERS: ALLOCATION, PLANNING, AND QUALITY ASSESSMENT FOR THE RYAN WHITE CARE ACT 91 (2004).

94 Centers for Disease Control and Prevention, *HIV Prevention Community Planning Guide* 15-16 (2003), *available at* http://www.cdc.gov/hiv/PUBS/hiv-cp.pdf (last visited July 22, 2005) [hereinafter "HIV Prevention Community Planning Guide"].

95 *Id.* at 16.

96 *Id.* at 17.

97 22 D.C. Mun. Regs. §§ 201.5; 206.2; 211.4 (2005).

98 *Id.* at § 200.4.

99 D.C. Code Ann. § 3-1205.14(a)(9) (2004).

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101 *Id.*

102 *Id.*

103 Interview with District of Columbia government official.

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107 *Id.*

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110 Testimony of Lydia Watts, Director, HIV/AIDS Administration, D.C. Council Committee on Health Oversight Hearing on the HIV/AIDS Administration (June 23, 2005).

111 *Id.*

112 Testimony of Lydia Watts, Director, HIV/AIDS Administration, and Remarks of David Catania, Chairman, D.C. Council Committee on Health, D.C. Council Committee on Health Oversight Hearing on the HIV/AIDS Administration (June 23, 2005).

113 Remarks of David Catania, Chairman, D.C. Council Committee on Health, D.C. Council Committee on Health Oversight Hearing on the HIV/AIDS Administration (June 23, 2005).

114 Testimony of Lydia Watts, *supra* note 110.

115 Remarks of David Catania, *supra* note 113.

116 Remarks of Ronald King, Interim Director, Prevention Division, HIV/AIDS Administration, HIV Prevention Community Planning Group Meeting (July 22, 2005).

117 Testimony of Gail Maureen Hansen, Interim Director, Surveillance and Epidemiology Division, HIV/AIDS Administration, and Ivan Torres, Former Interim Director, HIV/AIDS Administration, D.C. Council Committee on Health Oversight Hearing on the HIV/AIDS Administration (Mar. 17, 2005).

118 July 1 Telephone Interview with Dr. Matthew T. McKenna, *supra* note 91.

119 Telephone Interview with Dr. Matthew T. McKenna, Chief, HIV Incidence and Surveillance Branch, Div. of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention (July 14, 2005) [hereinafter "July 14 Telephone Interview with Dr. Matthew T. McKenna"].

120 HIV Unique Identifier System Amendment Act of 2005 (B16-0116) § 2, Council of the District of Columbia (2005), *available at* http://www.dccouncil.washington.dc.us/images/00001/20050211094055.pdf (last visited July 23, 2005).

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PART 2: CHAPTER IV

FUNDING AND GRANT MANAGEMENT

CHAPTER INFORMATION:

In addition to conducting HIV and AIDS surveillance, the government funds, coordinates, and oversees CBOs that furnish HIV/AIDS prevention and care services in the District. This chapter discusses the funding and shortcomings of HIV/AIDS services and the management of government grants to CBOs. It then makes specific recommendations for developing a centralized application process for the District's public benefit programs, expanding the prescription drugs covered by certain publicly-funded programs, maximizing enrollment in Medicaid, increasing Medicaid reimbursement for HIV/AIDS services, improving HAA's grant management process, and creating accountability mechanisms to improve the quality of services provided to District residents.

BACKGROUND

OVERVIEW OF FUNDING

HIV/AIDS prevention and care services are funded primarily through public sources. CDC and HRSA provide federal funds for HIV/AIDS services through grants to HAA, which in turn provides subgrants to CBOs. Medicaid and the Alliance reimburse CBOs and other health care providers for covered health care services furnished to eligible low-income patients who lack insurance. Medicare (which is available to the elderly and disabled) and private insurance also provide reimbursement to CBOs.

The District appropriates its own local funds to match certain federal health care coverage programs and fully funds the Alliance. In addition, local appropriations may be used to fund services independently of federal funding. In fiscal year 2005, the District appropriated over $9 million for personnel costs and services for HIV/AIDS.[141]

SAMHSA and HUD also provide funding for specialized services to those living with HIV/AIDS. SAMHSA provides funding for substance abuse prevention and treatment. HUD established the Office of HIV/AIDS Housing, which manages the Housing Opportunities for Persons with AIDS (HOPWA) program that funds programs addressing the specific housing needs of persons living with AIDS.[142]

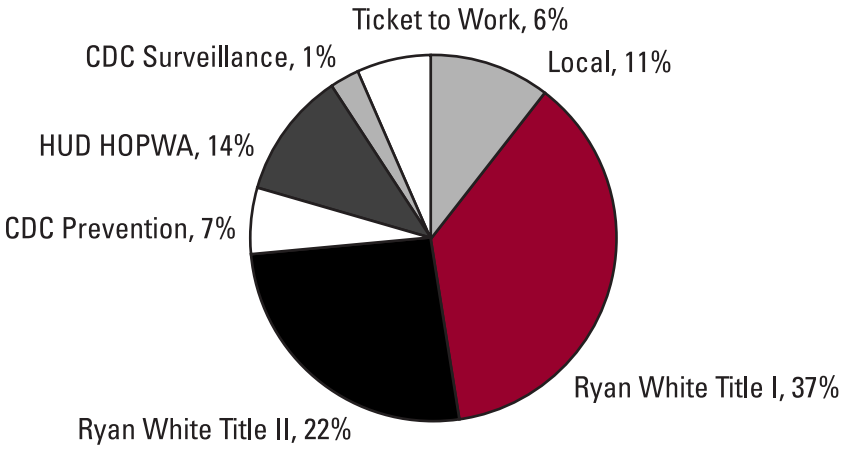
For fiscal year 2005, HAA's budget is $80,912,903, 89 percent of which is from federal sources.[143]

In addition to government-administered funds, private entities provide limited funding for HIV/AIDS-related services. Private foundations and other non-profit organizations play an important role in supporting HIV/AIDS service providers, particularly to fill gaps when there are restrictions on the use of public funds.

HIV PREVENTION FUNDING

CDC prevention grants are the major source of prevention funds for many jurisdictions, including the District. In order to receive a CDC grant, a jurisdiction must develop a comprehensive HIV prevention plan with the input of its HIV Prevention Community Planning Group (CPG); the development of this plan ensures community participation in the identification of funding priorities. Prevention planning must be evidence-based and incorporate views and perspectives of groups at risk for HIV, as well as providers of HIV prevention services.[144] The overall goal of a CPG is to identify the populations at high risk and in greatest need of prevention services, and to develop a prevention plan to guide the allocation of needed prevention resources.

Funding Sources for HAA



HIV/AIDS Administration Fiscal Year 2005 Budget, Presented by Sumita Chaudhuri, Administrative Services Manager, HIV/AIDS Administration, to the Mayor's HIV/AIDS Advisory Committee Meeting (Oct. 13, 2004).

To implement the HIV Prevention Plan funded by the CDC's grant, the District contracts with CBOs. The District's CDC prevention grant for 2005 totals $5,988,005. The CDC grant funds prevention services including counseling and testing, individual and group health education and risk-reduction programs, logistical support for the CPG, capacity building and training, and evaluation services. HAA is currently funding 13 subgrants for health education and risk-reduction interventions. The CDC also funds certain District-based CBOs directly on a competitive basis.

HIV/AIDS HEALTH CARE AND TREATMENT FUNDING

There are three principal funding sources in the District to pay for HIV/AIDS care and treatment services for the uninsured: Medicaid (for low-income persons who meet the eligibility requirements); the Alliance (for low-income persons who do not meet the Medicaid eligibility requirements); and the Ryan White CARE Act (which serves as a payor of last resort for certain HIV/AIDS services for individuals for whom no other source of funds is available).

MEDICAID

Medicaid is the joint federal-state health insurance program for certain low-income individuals. Medicaid serves as an important source of health care coverage for persons with HIV/AIDS, both in the District and nationwide. The District's Medicaid program currently covers over 140,000 beneficiaries.[145] In fiscal year 2001, 3,499 Medicaid beneficiaries in the District were estimated to be living with HIV/AIDS.[146] The District's Medicaid program is administered by the MAA, within the District's DOH. Eligibility for Medicaid is determined by the IMA, which is within the District's Department of Human Services.

Because the District receives 70 cents from the federal government for every dollar the District spends on Medicaid, the District has a strong incentive to maximize enrollment in Medicaid, rather than in programs funded solely with local resources. However, because federal matching funds are available only for certain categories of beneficiaries, the District must craft any attempted expansion of its Medicaid program carefully. The District's Medicaid eligibility requirements and benefits are discussed in detail in Appendix D. Of the publicly-funded

health care programs available to persons with HIV/AIDS in the District, Medicaid offers the best combination of services for beneficiaries, cost-effectiveness for the District, and long-term financial stability.

States can expand their Medicaid coverage and services by amending their state Medicaid plans or using Medicaid waivers and demonstration programs. Medicaid waivers allow states to receive federal matching funds for covering additional categories of beneficiaries or services that are not ordinarily eligible for matching funds. Demonstration programs are short-term tests of whether additional beneficiaries or services can be covered without increasing the Medicaid program's costs to the federal government. Both waivers and demonstration projects require approval from CMS, part of the U.S. Department of Health and Human Services (HHS), and are evaluated by CMS at their completion. The District currently has one waiver and two demonstration programs targeting persons with HIV/AIDS, described below.

SECTION 1915(C) WAIVER

The District currently has a Home and Community-Based Services waiver under Section 1915(c) of the Social Security Act exclusively for the benefit of persons with HIV/AIDS. Section 1915(c) allows states to waive Medicaid's usual requirements regarding financial eligibility, comparability of services, and statewide availability of services in order to provide home and community-based services. By waiving these requirements, states can use more liberal income and resource requirements for persons needing home and community-based services. All waivers must be approved by HHS, are subject to the state's usual federal match, and must be budget neutral. Specifically, the per capita expenses of services provided under the waiver must not exceed the costs of hospital, nursing home, or institutional care that would be provided if the waiver were not in place.[147]

The District's Section 1915(c) waiver, implemented in 2000, provides water filters to individuals with HIV/AIDS whose compromised immune systems may be harmed by contaminants in the water system.[148]

SECTION 1115 DEMONSTRATION PROJECT

Section 1115 demonstrations allow states to test policy ideas, such as providing care for a limited time period to additional populations that otherwise would not be eligible for Medicaid. The District's Section 1115 demonstration is intended to "provide more effective, early treatment of HIV disease by making available all Medicaid services, including antiretroviral therapies."[149] The Section 1115 demonstration was implemented on January 14, 2005,[150] four years after the Secretary of HHS approved the District's application for the project. District officials attribute the lengthy delay in the implementation of the Section 1115 demonstration to numerous logistical difficulties, including the establishment of a network of pharmacies for beneficiaries.[151]

During the five-year Section 1115 demonstration, up to 620 HIV-positive persons with incomes at or below 100 percent of federal poverty level (FPL) and resources within the categorically-needy limits will be allowed to enroll in Medicaid.[152] The program aims to offset the costs of this coverage expansion with the savings achieved from purchasing antiretrovirals for all HIV-positive Medicaid beneficiaries at the discounted prices uniquely available to the District.

As of March 17, 2005, all Medicaid beneficiaries were required to fill their prescriptions for antiretrovirals at the 24 participating Care Pharmacy Network stores. HAA uses a single application to determine a beneficiary's eligibility for the Section 1115 demonstration program, as well as both the Ticket to Work demonstration and the District ADAP program, which are described below.

TICKET TO WORK DEMONSTRATION

The District's most successful program to expand Medicaid coverage to persons with HIV/AIDS is its "Ticket to Work" demonstration project. The Ticket to Work and Work Incentive Improvement Act of 1999 allows states to use demonstration projects to provide Medicaid benefits and services to help working individuals control the progression of health conditions that may lead to disability. The District's Ticket to Work demonstration, one of only two such HIV-specific demonstration programs in the

nation, expands Medicaid eligibility to include persons with HIV who (1) work at least 40 hours per month; (2) have incomes under 300 percent of FPL; and (3) do not have job-related health insurance. The District program's enrollment is capped at 420 persons; HAA has filled the program and currently has a waiting list of 75 persons.

D.C. HEALTHCARE ALLIANCE

Many of the District's low-income residents who do not qualify for Medicaid, including single, childless adults, can receive health services through the Alliance. The Alliance is a public-private partnership funded by the District government for residents who lack health insurance and whose income is at or below 200 percent of the FPL. The Alliance's providers include four area hospitals and numerous primary care and specialty physicians. As of October 2003, 22,650 individuals were enrolled in the Alliance program.[154]

The purpose of the Alliance, created in 2001, is "to shift medical care from an emergency room and acute care setting to community-based health clinics and primary care physicians."[155] Many District residents historically relied on emergency rooms as the primary care provider for their health care services. The Alliance aims to change this practice by providing a network of primary care locations throughout the city, including private non-profit clinics, federally qualified health centers and hospital-affiliated clinics.[156] The eligibility requirements and benefits of the Alliance are discussed in Appendix D.

In addition to creating the Alliance, the District has undertaken a major effort to improve access to primary care in the city. The Medical Homes Project, funded by local and federal grants, is a 10-year project to expand the District's network of primary care clinics and providers and ensure a "medical home" for all District residents. A medical home is defined as "a primary care provider where a patient's health history is known, where a patient is seen regardless of ability to pay and where a patient routinely seeks medical care."[157]

RYAN WHITE CARE ACT

The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (Ryan White)[158] is an important source of federal funds for health care services for District residents with HIV/AIDS. Ryan White services are intended to reduce costly inpatient care, increase access to care for underserved populations, and improve the quality of life for those affected by the epidemic. Ryan White funds local and state programs that provide primary medical care and support services, health care provider training, and technical assistance to help funded programs address implementation and emerging HIV/AIDS care issues.

Ryan White funding[159] is administered at the federal level by HRSA. Ryan White functions as a payor of last resort for those individuals who cannot cover the costs of their care and for whom no other source of payment for services, public or private, is available.[160] The District received over $15 million in Ryan White funding in fiscal year 2005.[161] Ryan White funds are administered based on the funding priorities established by the Ryan White Planning Council, described in Chapter II above.

The CARE Act is scheduled for Congressional reauthorization in 2005. AIDS advocates expect Congress to consider several changes to Ryan White programs, including new methods of allocating funds, requirements for services to be provided, and definitions of communities that are eligible to receive funding. The services and funding options described in this report could be affected by these changes.

Ryan White provides funding for the AIDS Drug Assistance Program (ADAP). ADAP is administered by states using a combination of state and federal funds.[162] The program provides access to HIV/AIDS prescription drugs for low-income people who are uninsured, unable to obtain adequate prescription drug coverage through a private insurer, and are ineligible for Medicaid and Medicare. For many impoverished people, ADAP is the only source of HIV-related medications.[163] States determine which drugs to include on the program formulary and programs vary in medical and financial eligibility requirements.

HAA operates the District ADAP[164] program primarily using federal funding; the District's contribution is only 3 percent of the total ADAP budget. The District also benefits from access to discounted drug prices, which are unavailable to state ADAPs.[165]

GRANT MANAGEMENT

To properly administer the multiple funding streams for HIV/AIDS services in the District, HAA must have a functioning grants management system in place. Grantees should be paid in a timely manner and grant renewals should be expeditiously processed. Furthermore, appropriate monitoring of grantee compliance with grant award terms must exist. In addition, HAA should conduct regular program outcome monitoring of grantees to ensure that the program is effectively reaching its objectives. For grantees providing care services to clients with HIV/AIDS, a quality assurance system should be instituted to ensure quality care.

GRANT AWARD PROCESS

HAA distributes funding, both federal and local, through grants to dozens of organizations that provide HIV/AIDS care and treatment and prevention services. In the case of federally-funded grants, HAA applies for funding and receives a notice of grant award from the federal grantor. After placing a notice of funding availability in the D.C. Register, HAA releases a request for application. An external review panel scores applications submitted by CBOs, and HAA then convenes an internal review panel to review the external scoring and proposals. After HAA reaches final decisions on grant awards, it requires that grantees sign agreements setting out the terms of the award before commencing the provision of services.[166]

GRANT MONITORING

Jurisdictions receiving federal grants must monitor the compliance of subgrantees with both program and fiscal requirements.[167] Subgrantees must meet the performance goals listed in the grant, and they must employ fiscal controls to ensure use of awards for the authorized purpose.[168] Some monitoring mechanisms include: progress reports, site visits, financial reports, and financial audits by the jurisdiction or a third party.[169]

QUALITY ASSURANCE

PROGRAM OUTCOME MONITORING

Program outcome monitoring typically entails before-and-after assessments of interventions with individuals and groups to determine the extent to which the particular intervention achieved changes in expected behavior. This differs from formal outcome evaluation, in which the particular intervention is isolated to determine a causal relationship between the intervention and changes in behavior.[170] However, the CDC has compiled a list of evidence-based interventions, and requires public health agencies to fund only those interventions that have been proven effective, so that formal outcome evaluation is not necessary.[171] Program outcome monitoring is necessary to ensure that that the funded program's objectives for its target population are being met.

QUALITY OF CARE

Given the complexity of health issues associated with HIV/AIDS, which will be discussed in Chapter VI, it is critical that persons with HIV/AIDS receive quality care services. Quality assurance programs can ensure that providers give adequate HIV/AIDS care, which can prevent patients from developing serious and costly health complications. Any quality assurance program must begin with the development of relevant standards.[172]

FINDINGS AND RECOMMENDATIONS

FUNDING

SINGLE POINT OF ENTRY

The first challenge facing an individual with HIV/AIDS seeking medical benefits is the enrollment process. Currently, many of the District's various publicly-funded health care programs use separate enrollment procedures. The Section 1115 demonstration,

the Ticket to Work demonstration, and ADAP share a single four-page application, which is processed by HAA. Enrollment in Medicaid outside the HIV/AIDS demonstrations, however, requires a different six-page application, processed by the IMA. The Alliance uses a third application, which is collected at participating clinics and processed by a contractor. District officials report that IMA will process a single application for Medicaid and the Alliance starting in spring 2006.[173]

Multiple enrollment requirements may confuse beneficiaries and discourage them from completing the paperwork necessary to receive their benefits. Although individuals may not qualify for the first program to which they apply, they could qualify for another program. All of the District's public benefits programs should coordinate enrollment procedures and referrals to help direct beneficiaries to the correct programs. Although combining the Alliance and Medicaid applications is a good first step, more can be done. Since the District intends to integrate the enrollment process for these two programs, only a limited amount of additional funding would be necessary to implement a true single point of entry system.

Complicated and uncoordinated enrollment processes not only diminish the chance that eligible recipients will be served, they also cost the District significant amounts of money. Although the Alliance is supposed to verify that an applicant is not eligible for Medicaid before enrolling the beneficiary, some patients who are eligible for Medicaid have nevertheless been enrolled in the Alliance, at great cost to the District. For example, in 2001, MAA reported that 1,382 Alliance patients were also enrolled in Medicaid.[174] The OIG determined that the District would have needlessly spent over $284,000 if this enrollment error had not been discovered.[175] District officials report that MAA compares Medicaid enrollment with Alliance enrollment every two weeks to minimize duplicate enrollment. The District should continue to ensure that Medicaid-eligible residents are enrolled in Medicaid, not the Alliance.

Recognizing these challenges, the DOH has attempted to develop its own "single point of entry" system. In this system, an individual attempting to access benefits at a provider site or through HAA must first apply for ADAP benefits.[176] The ADAP office then enters the application data into a database system called XPRES.[177] The XPRES system screens the application data for eligibility in the various public benefit programs, including Medicaid and the Alliance.[178] If eligible for ADAP, the applicant is enrolled in ADAP by HAA.[179] If the applicant is eligible for Medicaid or the Alliance, the individual is referred to IMA or the Alliance to complete the appropriate application process.[180] Once the applications for Medicaid and the Alliance are combined, HAA will presumably provide a single referral to IMA for enrollment in both programs.

A true single point of entry is a system in which *one* application is processed by one agency to determine eligibility and benefits for *every* publicly-funded health care program. In contrast, HAA's current model facilitates only limited access and referrals to other programs. Often, an individual applicant must still complete multiple applications. A true single point of entry would require additional integration and coordination between providers, HAA, IMA, and the Alliance to ensure that the applicant receives the necessary benefits through a single application. For example, the application for these health coverage services should be processed through a single database system. With such a system, there would need to be appropriate protections to ensure that each agency only has access to the data necessary for its program and staff using the system would need to receive confidentiality training.

THE DISTRICT'S AIDS DRUG ASSISTANCE PROGRAM

The District ADAP eligibility requirements are among the most generous in the nation.[181] Residents with incomes up to 400 percent of the FPL ($38,280 for a single person in 2005) are eligible to enroll in the District ADAP, and like most states, the District ADAP requires only documentation from a physician confirming an individual's HIV-positive status or a copy of the positive HIV test result.[182] In contrast, some states' financial eligibility thresholds are set as low as 200 percent of FPL. Other states, including Arkansas,

Georgia, and Virginia, require that the applicant establish that he or she meets certain CD4 cell count or viral load requirements prior to enrollment in the program.[183] By not requiring individuals to meet a prescribed CD4 cell count or viral load, the District ADAP assures that every HIV-positive District resident who is financially eligible may enroll in the program.[184] The District ADAP also has no waiting list for access to the program and no enrollment caps or per capita spending limits are planned or in place.[185] The accessibility of the District's ADAP program is commendable.

Some consumers have criticized the District's ADAP formulary. The formulary currently covers 67 prescription drugs. The formulary includes HIV/AIDS treatments, including all of the approved antiretrovirals, as well as other medicines that treat opportunistic infections.[186] Consumers in focus group meetings organized by DC Appleseed reported that D.C.'s ADAP does not cover a sufficient number and variety of drugs to treat opportunistic infections and other conditions. D.C.'s ADAP formulary includes 47 such drugs, while the Connecticut ADAP formulary includes 138 drugs.[187] If sufficient funding is available, consideration should be given to expanding D.C.'s ADAP formulary.

MAXIMIZING MEDICAID ENROLLMENT

The OIG issued a report in June 2005 noting that the failure of three subgrantees to obtain Medicaid certification "resulted in the District losing the opportunity to receive $1.1 million in federal reimbursements from Medicaid."[188] HAA should ensure that all subcontractors that provide Medicaid-covered services be certified Medicaid providers. This would ensure that Ryan White funds are not used to provide services that could be reimbursed by the Medicaid program.

MEDICAID REIMBURSEMENT FOR HIV/AIDS SERVICES

Providers report that the District's Medicaid reimbursement rates are extremely low. Medicaid pays between $35 and $90 per office visit, while the cost per visit is estimated to be $135 to $150.[189] By contrast, New York instituted a multi-tiered reimbursement system in 1989 that has significantly increased Medicaid reimbursement for HIV/AIDS services.[190] For example, Medicaid reimbursement for intermediate level office visits for patients with HIV/AIDS was raised to $276 from $67.50.[191] MAA should explore the implementation of a similar system of augmented Medicaid reimbursement for District HIV/AIDS services.

GRANT MANAGEMENT

GRANT PAYMENT PROCESS

Most CBOs depend on timely receipt of grant funding from government agencies to support the uninterrupted provision of services. Unfortunately, HAA's slow grant approvals and renewals, delayed payments, and burdensome audit requirements make it difficult for many of these organizations to fulfill their obligations under their subgrants.

Delays in grant payments make it difficult for organizations to provide care while also meeting their rent and payroll obligations.[192] Many of the District's HIV/AIDS service providers are small, non-profit groups that are heavily reliant on their subgrants from HAA and do not have the resources to remain open for months without payment. The D.C. Council Committee on Health held hearings on May 18 and 25, 2005 to address longstanding, pervasive payment delays that jeopardize the provision of HIV/AIDS care and other services to District residents. Representatives from numerous CBOs testified that HAA reimbursements for grant expenditures are consistently late and often several months past due. At the May 25 hearing, DOH Director Gregg Pane and HAA Administrator Lydia Watts committed to streamlining the grant payment process and ensuring payment within a 20- to 30-day period from the submission of necessary documentation.[193] At a follow-up hearing on June 23, 2005, reports from HAA and CBOs suggested that improvements had been made to the payment system.

The hearings demonstrate how focused public attention and commitment of Executive Branch resources can spur agency action. Both the Council and the Mayor's office should require that HAA meet the accelerated payment schedule and continue

to publicly address these and other vital issues related to HIV/AIDS care and services.

GRANT AWARDS AND RENEWALS

Various providers have reported that HAA is slow in processing grant announcements and renewals, even for longstanding subgrantees.[194] HAA's delays in processing grant renewals can jeopardize access to care. HAA should process grant renewals in a timely manner to ensure that CBOs can provide continuous services to individuals living with HIV/AIDS.

GRANT MONITORING

In addition to payment delays, testimony by HAA, the OIG, and several subcontractors at a March 17 hearing revealed that HAA's grant monitoring procedures often are not followed and result in payment to subcontractors for services they may not have provided.[195] The OIG's final report indicates that HAA kept inadequate and inaccurate records of site visits and failed to perform many required visits.[196] HAA's grant monitoring policy requires at least four site visits per year to each grantee.[197] HAA grant monitors reported that they typically conduct only two site visits per year due to time constraints.[198] Yet, the OIG audits also indicate that HAA's 10 grant monitors, each of whom has an average caseload of nine subgrantees, are in fact sufficient to complete the four requisite site visits per year.[199]

The auditors found significant problems beyond the failure to perform site visits. There was no evidence of HIV/AIDS services being provided at two grant sites, and some grant monitors did not know the current locations of some subgrantees they were responsible for monitoring.[200] In addition, the OIG found that HAA grant monitors did not discover until the conclusion of the grant award that several subgrantees fell short of meeting their targets for delivering services as described in their grant agreements.[201] The OIG also determined that 19 providers were unauthorized to provide services in the District either because their incorporation documents had been revoked or because they did not have the required business licenses.[202] The OIG suggests that inadequate grant monitoring is the result of insufficient training and supervision of HAA grant monitors and a lack of internal controls at HAA.[203] DOH's response to the OIG report contains specific steps for instituting internal controls to ensure that current grant monitoring policies will be followed.[204] DOH should move quickly to adopt necessary internal controls and the OIG's recommendations.

QUALITY ASSURANCE

PROGRAM OUTCOME MONITORING

In addition to monitoring existing grant requirements, HAA should establish and implement comprehensive program outcome monitoring requirements to evaluate whether funded prevention and care programs are effectively meeting District needs. For example, HAA should require CBOs to conduct pre- and post-intervention tests in order to assess the impact of prevention interventions.

HAA staff has reported that program monitoring has been difficult due to poor data collection.[205] However, to improve collection of data regarding prevention interventions from CBOs and comply with a CDC mandate, HAA recently implemented the CDC's Program Evaluation and Monitoring System (PEMS) on June 10, 2005.[206]

HAA officials note that monitoring and continued training for providers regarding the regular collection and input of accurate data into this database will be a challenge.[207] Nevertheless, HAA should use data collected through PEMS to assess program outcomes and work with CBOs to develop strategic plans for improving services.

QUALITY OF CARE

In order to ensure that all people living with HIV/AIDS receive the quality of care they need, it is necessary for all implicated agencies to increase accountability and oversight and to impose outcome measures on the programs they administer. HAA recently began the process of developing more outcome measures and standardization across its service areas due to last year's mandate by HRSA to implement a "Quality Management Plan." In cooperation with the Ryan White Planning Council, HAA staff has developed quality assurance standards that are included in grant agreements;

compliance with the standards is subject to periodic evaluation.[208] In 2003 and 2004, HAA staff reviewed the medical records of 20 providers for a number of quality assurance indicators for primary care, case management, mental health, and substance abuse.[209] DC Appleseed did not evaluate the appropriateness of HAA's quality assurance standards or the adequacy of the provider reviews.

Once basic standards have been developed, several options exist for implementing quality assurance. For example, recognizing that limited staff resources can challenge provider ability to evaluate and measure services, the HIV/AIDS Planning Council staff in Seattle includes an Assessment Coordinator that agencies are encouraged to use as a technical assistance resource. The District could also utilize incentives to ensure adherence to developed standards. Some incentive programs, including several now being tested by Medicare,[210] offer providers additional payments for reporting data on their performance on specific quality measurements. Others reward providers who meet standards with bonus payments or penalize providers who fail to meet the standards by reducing their reimbursement. There currently is a great deal of interest on the part of health policy experts in such "pay-for-performance" approaches.[211]

The District Medicaid and Alliance programs could be used to collect data on the quality of care and outcomes for persons living with HIV/AIDS. For example, the District could propose a Medicaid demonstration program to offer additional payments to providers who report data on critical health care measures for persons with HIV/AIDS, such as adherence to drug regimens, and control of diabetes, heart disease, and opportunistic infections, and patient education. These data would help the District monitor the quality of care provided and could lead to the development of quality-based payment systems. Once the District has data on the quality of care currently provided, it could implement a second phase of the demonstration whereby providers would be given higher reimbursement for meeting certain predefined quality standards. The District should explore with CMS, providers, and standard-setting organizations whether such a program is feasible.

SUMMARY OF RECOMMENDATIONS

Single Point of Entry Enrollment. The District should develop a centralized application process, to be administered by IMA, for enrollment and eligibility verification for Medicaid, the Alliance, Ticket to Work, ADAP, and other programs.

Expand ADAP Formulary. If sufficient funding is available, the District should consider expanding the ADAP formulary to include a greater number of drugs to treat opportunistic infections and other conditions.

Maximize Medicaid Enrollment. The District should use funding sources more efficiently by maximizing enrollment in Medicaid. Providers should ensure that patients are enrolled in the Medicaid program if they are eligible. Furthermore, the District should develop specific protocols for verifying Medicaid eligibility and ensuring that all subcontractors that provide Medicaid-covered services are certified Medicaid providers.

Increase Medicaid Reimbursement. The District should explore the possibility of increasing Medicaid reimbursement for HIV/AIDS services.

Grants Management. HAA should ensure prompt payment of grants and should evaluate the newly developed payment process for timeliness. Furthermore, HAA should ensure grant renewals are expeditiously processed. HAA should also promptly adopt internal controls to ensure adequate grant monitoring as recommended by the OIG.

Quality Assurance. HAA should implement a comprehensive system of program outcome monitoring, utilizing the data collected through PEMS to assess the effectiveness of funded prevention interventions. In addition, relevant payors, including Medicaid and the Alliance, should consider linking payment for care to measurable performance standards. Furthermore, the District should explore a possible Medicaid demonstration program that would involve "pay for performance" incentives for higher quality HIV/AIDS care.

CONCLUSION

Improving services for people with HIV/AIDS in the District requires the most efficient use of funding. DOH should maximize the use of existing funds by ensuring that individuals are enrolled in the appropriate health coverage programs. CBOs must be paid sufficiently and in a timely manner to secure the stable provision of services. In addition, HAA should develop more effective accountability mechanisms to ensure effective prevention and quality care services.

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PART 2: CHAPTER V

HIV PREVENTION

CHAPTER INFORMATION:

Continuous surveillance of the HIV/AIDS epidemic and an understanding of the relevant risk behaviors are necessary to formulate effective prevention interventions.[212] Prevention interventions aim to modify an individual's behavior in order to reduce the risk of contracting or infecting others with the virus. A number of HIV prevention interventions have been scientifically proven to modify behavior and reduce the transmission of HIV.[213] Successful interventions promote responsible decision making by all individuals, so that they can avoid engaging in risk behavior. Such prevention efforts are a critical component of a comprehensive response to the HIV/AIDS epidemic.

One effective way of promoting prevention is through HIV testing programs. Such programs identify people who are infected with HIV so that they can obtain medical care and other services. In addition, testing provides an opportunity to counsel HIV-positive and HIV-negative individuals about behavior modification and risk-reduction strategies so that individuals can take responsibility for avoiding transmission of the virus.

This chapter describes HIV prevention tools, testing and counseling, prevention case management, and STD prevention. Furthermore, this chapter explains how the District's prevention efforts need to be broadened and strengthened to more effectively address HIV/AIDS. Recommendations include the promotion of routine and rapid HIV testing, increased condom distribution, and expanded STD Clinic services. Subsequent chapters discuss prevention recommendations related to specific populations, including youth, drug users, and the incarcerated.

BACKGROUND

HIV PREVENTION TOOLS

HIV prevention aims to avoid new HIV infections. According to the CDC, successful "HIV prevention efforts must be comprehensive and science-based."[214] A comprehensive HIV prevention program is based on surveillance, community planning, and education, and includes CDC-endorsed interventions such as: HIV counseling, testing, and referrals; health education; harm/risk reduction; and capacity-building activities.[215]

Commonly used HIV prevention tools include the following:

- **HIV prevention counseling, testing, and referral (CTR)** are client-centered services delivered to persons who undergo anonymous or confidential HIV testing. The services aim to identify an individual's HIV status and risk behaviors and make appropriate referrals.
- **Harm/risk reduction** is an intervention aimed at reducing the risk of HIV transmission by injection drug use and/or sexual behavior. Examples of harm reduction interventions include the promotion of the use of condoms to prevent sexual transmission of HIV and the use of clean syringes to prevent transmission among IDUs.
- **Outreach activities** are services delivered to persons at high risk for HIV in places they are likely to gather or frequent. Such outreach is aimed at individuals and often is provided in locations not directly related to HIV prevention or health services, such as bars and clubs.
- **Partner counseling and referral services** involve confidential and voluntary notification of an HIV-positive individual's

past and present sex or syringe-sharing partners of possible exposure to HIV. In addition, a partner may receive counseling and education on how to avoid HIV and STD infection.

- **Social marketing** uses commercial marketing techniques to promote HIV prevention in a population or sub-population. These techniques are aimed at "selling" socially beneficial ideas, behaviors, and practices, and may be applied to all types of HIV prevention interventions. Social marketing may include the distribution of brochures and educational materials.[217]
- **Prevention case management** involves multiple one-on-one sessions of risk-reduction counseling using a variety of strategies to change an individual's sexual and other risk behavior.

According to the CDC, each HIV prevention intervention effort should have a defined audience, clearly stated goals and objectives, a focus on risk behaviors, and a specific setting.[218] For example, an HIV prevention program could be aimed at IDUs, with the goals of increasing condom use and use of sterile injection equipment.[219] Such a program may include counseling, clean syringe exchange, condom distribution, education, or testing, and may be most effective in a street setting or community venue where the targeted group can be found.[220]

Community organizations can play an important role in raising awareness of HIV/AIDS prevention measures through informal education and interactions. For example, faith-based organizations and organizations serving high-risk populations should discuss safe sex and abstinence and reinforce prevention messages. In addition, community organizations should distribute condoms and educational materials.

DC Appleseed did not evaluate the use or efficacy of particular interventions or informal prevention efforts by community organizations in the District.

ADVANCING HIV PREVENTION (AHP)

Recently, the CDC developed the "Advancing HIV Prevention" (AHP) initiative.[221] This new paradigm has several implications for funding of HIV prevention programs in the District and may affect the specific types of interventions that are used in prevention programs.

The new AHP initiative prioritizes interventions aimed at people living with HIV – "prevention with positives."[222] In connection with this shift in focus to HIV-positive individuals, the CDC has issued recommendations for incorporating HIV prevention into the routine medical care of persons living with HIV.[223] These recommendations focus on three major areas: risk screening; behavioral interventions; and partner counseling and referral services.[224]

CDC'S ADVANCING HIV PREVENTION (AHP) STRATEGIES:

1. Make HIV testing a routine part of medical care;
2. Use new models for diagnosing HIV outside of traditional medical settings;
3. Prevent new infections by working with HIV-positive persons and their partners; and
4. Decrease maternal-fetal HIV transmission.

Centers for Disease Control and Prevention, *Advancing HIV Prevention: Interim Technical Guidance for Selected Interventions* 3.

TESTING AND COUNSELING

Testing for HIV status is a critical component of the AHP initiative and the effort to stem the spread of HIV locally and nationwide. Since 2003, the CDC has recommended that HIV screening be incorporated into the routine medical care offered in facilities serving individuals with high HIV prevalence, akin to cholesterol or other regular health screenings.[225]

The CDC estimates that up to 25 percent of those infected with HIV are unaware of their HIV status.[226] Studies indicate that the majority of individuals who know that they are HIV-positive take effective steps to reduce the risk of spreading the infection to others.[227] Therefore, the earlier one discovers he or she is HIV-positive, the earlier that person is likely to adopt risk-reducing behaviors that will help prevent the further

PREVENTION WITH POSITIVES IN THE MEDICAL SETTING:

- Risk Screening
  - – Behavioral risk screening
  - – Clinical (STD) screening
  - – Pregnancy screening
- Behavioral Interventions
  - – Prevention messages in clinical setting
  - – Reinforcement
  - – Dispel HIV/AIDS misconceptions
  - – Target high risk individuals
  - – Make referrals
- Partner Notification, Counseling, and Referral Services

Advancing HIV Prevention Interim Technical Guidance for Selected Interventions 2-3.

spread of the virus. Testing also is extremely important to improving the health and quality of life of those who are HIV-positive. The earlier in the course of infection that a person discovers he or she is HIV-positive, the better his or her chances are to obtain effective treatment to prevent or postpone the onset of AIDS. Unfortunately, many people infected with HIV discover their HIV-positive status only after the infection has progressed to AIDS and many opportunities to treat the infection have been missed.

It can take six months or longer after the time of infection for an individual to test positive for HIV.[230] An individual who tests negative but has experienced even a single known or possible exposure to HIV should generally be re-tested within six months after the last known possible exposure to the virus.[231] People who repeatedly engage in high-risk behavior should be tested regularly.

TESTING AVAILABILITY

HIV testing is performed by private doctors, hospitals, HAA, the STD Division, CBOs, and at the District's detention facilities. Project Orion, a mobile medical outreach unit funded jointly by HAA and APRA, travels to high-risk areas offering HIV testing, counseling, and referral services.[232] HAA also participates in health fairs and community events, offering information and testing opportunities to the public. HIV counseling, testing, and referral services are offered at no cost to individuals by the DOH. Additionally, HAA funds five CBOs to provide counseling, testing, and referral services and operates an HIV testing information hotline.

TRADITIONAL VERSUS RAPID TESTING

The traditional test for HIV antibodies is performed on a blood specimen.[233] If the result is positive, a second test is used to confirm the positive result.[234] Although the traditional testing methodology is highly reliable, it involves significant disadvantages. The individual being tested must submit to a blood draw, which may make some people reluctant to be tested. It also takes up to two weeks to obtain results from traditional testing.[235]

The delay in obtaining test results from traditional testing is a serious drawback because individuals need to return to the testing site for their test results. Of course, the benefits of testing are lost if the person tested does not learn his or her HIV status. In 2003, 33 percent of all those tested in the District did not return for their HIV test results.[236] Traditional testing is particularly problematic when an individual who has tested positive for HIV does not return for the test results. In 2003, 18 percent of those who tested positive for HIV in the District did not return to receive their results.[237] Because many individuals fail to return for their traditional test results, post-test counseling and HIV treatment and care may be delayed or may never happen.

Fortunately, in recent years there have been important advances in rapid testing for HIV. Rapid testing represents a major improvement over traditional testing. Instead of requiring a blood draw, rapid tests can be performed with only a few drops of blood from a finger stick or a sample of oral fluid.[238] This allows rapid HIV testing to be performed in non-clinical settings, such as community centers and health fairs. Preliminary results are available in 20 minutes,[239] eliminating the need for individuals to return for results at a later date, which has been a consistent problem at testing sites. Prompt availability of results significantly increases the number of people tested who actually learn their HIV status.[240] In addition, testing sites that have implemented rapid testing have reported an

increase of up to 30 percent in testing among high-risk populations.[241]

PRE- AND POST-TEST COUNSELING

CDC considers pre- and post-test counseling to be essential components of HIV prevention.[242] During pre-test counseling, the counselor provides information concerning informed consent and confidentiality and information about the test itself.[243] The counselor also discusses the client's risk behaviors and risk-reduction methods.[244] During post-test counseling, the counselor provides and explains the test results, discusses relevant risk and prevention information, reviews risk-reduction methods, and refers high-risk individuals to further prevention counseling.[245] If the client's test result is positive, post-test counseling includes treatment and case management referrals.[246] Counselors also attempt to gather information to encourage partner notification.[247]

CONDOM DISTRIBUTION

One of the most basic and universally recognized prevention interventions to reduce transmission of HIV is the promotion of condom use. Condoms, when used consistently and correctly during sexual intercourse, can reduce the risk of transmitting and contracting HIV and other STDs.[248] Studies have shown that male condoms are up to 95 percent effective in reducing the transmission of HIV.[249] Female condoms are up to 97 percent effective in reducing the risk of HIV infection when used correctly and consistently.[250]

Efforts to reduce HIV transmission through condom use have focused on expanding access to condoms, providing education on proper condom use, and promoting regular and consistent use of condoms. The broad distribution of condoms should be combined with targeted prevention interventions, such as peer education for sex workers, in order to maximize the effectiveness of this prevention method.[251]

SEXUALLY TRANSMITTED DISEASE PREVENTION AND TREATMENT

In order to be an effective HIV prevention intervention, STD treatment must be continuous and integrated into primary care delivery. In 1998, CDC's Advisory Committee for HIV and STD Prevention (ACHSP) reported strong evidence that early detection and treatment of STDs is an effective strategy for preventing HIV infection.[252] ACHSP recommended expansion of existing screening and treatment programs, particularly in areas with high STD and HIV rates and increased coordination between HIV and STD prevention programs. ACHSP also recommended routine STD screening and treatment in primary health care settings, and in non-medical settings, such as correctional facilities and substance abuse treatment centers.

STD prevention is particularly important as an HIV prevention tool for certain populations. Due to the stigma and misconceptions associated with HIV-positive status in some communities of color, prevention education for STDs often is more acceptable than HIV-specific education as a health care tool.[253] Prevention education messages that combine HIV, STD, and unwanted pregnancy may be particularly effective with young people.[254] Additionally, STD prevention can be an important HIV prevention tool for women because STD infections increase their vulnerability to HIV, but may go undetected since they often are asymptomatic.[255]

PREVENTION CASE MANAGEMENT

Prevention case management is a support service for individuals who are at high risk of transmitting or acquiring HIV, but who are having difficulty initiating or sustaining behavior that reduces or prevents HIV transmission or acquisition.[256] Unlike prevention activities such as outreach and support groups in which staff may interact briefly with high-risk individuals, prevention case management involves multiple one-on-one sessions of risk-reduction counseling using a variety of strategies to change HIV risk behavior. Like traditional case managers,

prevention case managers connect clients with needed medical and psychosocial services; but, unlike traditional case managers, prevention case managers focus specifically on services that influence HIV risk-taking (e.g., STD and substance abuse treatment). For example, an IDU "may have difficulty benefiting from HIV risk-reduction counseling without receiving substance abuse treatment."[257] For individuals who are HIV positive, prevention case management is most effective when prevention interventions are coordinated in close collaboration with Ryan White case managers.[258]

FINDINGS AND RECOMMENDATIONS

TESTING

ROUTINE HIV TESTING

HIV testing presents an opportunity to educate individuals about HIV prevention practices and to refer HIV-positive individuals to care services. Detection of HIV infection in the early stages of the disease followed by prompt entry into care can lead to timely initiation of an appropriate treatment regimen.[259] Treatment slows the progression of HIV to AIDS and increases survival rates of those living with AIDS.[260] The CDC's AHP Initiative recommends implementation of routine testing, which the CDC defines as ensuring "that all healthcare providers include HIV testing, when indicated, as part of routine medical care on the same voluntary basis as other diagnostic and screening tests."[261]

Routine testing was found to be cost-effective in two recent studies published in the *New England Journal of Medicine.* One of the studies estimates that routine HIV testing generally would reduce the annual transmission rate by slightly more than 20 percent.[262] In addition, both studies indicate that routine testing extends survival by one-and-a-half years for the average HIV-positive patient.[263] By reducing HIV transmission rates and extending survival, routine testing decreases the amount of productivity lost because of HIV infection.[264]

Currently, no District-wide strategy for implementing routine HIV testing exists. The District does, however, promote routine testing of pregnant women on an opt-in basis. HAA is in the process of revising its policy on the routine HIV testing of pregnant women to state explicitly that HIV testing should be provided on an opt-out basis. Under an opt-out approach, a pregnant woman is informed that an HIV test will be performed unless she declines the test. The opt-out approach leads to a greater number of tests compared with an opt-in approach, in which the client is asked if she would like to undergo the test.[265] HAA should expedite the revision of the policy on HIV testing of pregnant women.

In addition to revising the policy for pregnant women, HAA should broaden routine testing to include high-risk populations. Although testing is available at the STD Clinic and APRA sites, HAA should take immediate steps to collaborate with the STD Clinic, APRA substance abuse detoxification and treatment centers, the District TB Clinic, and DMH-funded providers to ensure that HIV testing is offered *routinely* to all clients, given the high-risk populations being served. HAA also should collaborate with the MAA and the Alliance to promote and ensure that HIV testing is a routine part of primary medical care for those with public health coverage. In addition, HAA should work with the Board of Medicine and the Medical Society to promote testing at *all* medical settings for the privately insured.

Furthermore, HAA should promote routine testing in emergency rooms. Recent studies of pilot programs in Atlanta and Boston support the provision of routine testing in emergency rooms in high-risk prevalence areas.[266] In Atlanta, the number of patients tested, the number of HIV infections detected, and the number of HIV-positive patients entering care were significantly higher where routine testing was provided.[267] A pilot project in Boston also indicated that routine testing was more cost-effective than traditional self-referral testing.[268]

The District may benefit from other ongoing studies of routine testing. In April 2004, the CDC initiated demonstration projects in Wisconsin, Massachusetts, New York State, and Los Angeles County to implement

widespread routine testing using rapid HIV tests in "non HIV related" medical care settings.[269] The projects seek to develop model programs that will identify barriers to effective routine testing and demonstrate the feasibility of implementing routine rapid HIV testing. The CDC will use the findings from these projects to develop guidelines that can further inform the District's efforts to expand routine HIV testing.[271]

RAPID TESTING

In addition to promoting routine testing, the District should ensure widespread availability of rapid testing. HAA began to offer rapid testing in 2003, and some CBOs began offering rapid testing in late 2004.[272] HAA currently offers the rapid test at its office, and provides funding for rapid testing at two CBOs.[273] In 2005, HAA also plans to train three additional CBOs to provide rapid testing.[274] HAA estimates that, in 2005, HAA and these organizations collectively will administer 10,000 rapid tests.[275] Rapid testing also is available at many CBOs through direct funding from the CDC and SAMSHA.[276] In 2005, HAA and APRA implemented a Rapid HIV Testing Initiative for high-risk populations, which the Bureau of STD is expected to join later this year.[277] DOH should continue efforts to conduct rapid HIV testing at all District facilities, including the STD Clinic, all APRA sites, the TB Clinic, and the D.C. Jail. In addition, HAA should provide training so that all grantees may implement rapid testing.

Implementation of rapid testing should save the District money, since rapid tests cost less than traditional tests. One manufacturer quoted the cost of the rapid test at $17 per test, whereas its traditional oral test costs $24 per test.[278] In addition, a 2003 study that analyzed the cost of administering HIV tests suggests that rapid testing is significantly cheaper than traditional testing.[279]

CONDOM DISTRIBUTION

The District's condom purchasing and distribution efforts require expansion and improvement. Widespread, regular condom distribution is a proven, cost-effective prevention intervention, as demonstrated by a state-wide condom distribution and social marketing program in Louisiana. The Louisiana program has distributed about 13 million condoms per year at various locations, including hospitals, public and private clinics, salons, bars, and restaurants.[280] A study of the Louisiana program demonstrated that the availability of condoms increased condom usage and estimated that the saved medical costs from preventing one new case of HIV/AIDS pays for more than 15 million condoms.[281] Among African Americans, the program was shown to be particularly effective, resulting in a 30 percent increase in condom use. Overall, the program was estimated to have prevented 170 HIV infections in the program's first three years, resulting in a potential savings of $33 million in medical care costs.[282] Based on Lousiana's experience, an expanded condom distribution program may be an extremely cost-effective means of reducing HIV transmission in the District.

In December 2003, the Acting Director of HAA publicly announced that HAA would distribute 550,000 male condoms, 45,000 dental dams, and 30,000 female condoms throughout the city during 2004.[283] At that time, HAA began a condom distribution initiative called "Safe-in-the-City" to distribute condoms and install condom machines in 14 local bars and clubs.[284] Despite the stated distribution goal, HAA staff estimates that 140,000 condoms were distributed through the Safe-in-the City Initiative and 120,000 to 150,000 through outreach efforts at health fairs and other events in 2004.[285] Due to recent funding cuts, the initiative has been reduced to four large "mainstream" clubs for 2005.[286] In addition, HAA staff reports that HAA provides condoms for distribution in beauty shops in the District.[287]

Given the high local AIDS rates and the scientifically proven effectiveness of condom use in preventing HIV transmission, condom distribution should be a priority of the District. At best, HAA distributed 290,000 condoms last year, about 50 percent of HAA's own projected target. Other cities, such as New York City, are giving a very high priority to condom distribution in a variety of venues, including nightspots, clinics, barbershops, beauty salons, movie theaters, hotels, hospital emergency rooms, government offices, and public restrooms.[288]

In addition to increasing its own distribution initiatives, HAA should develop a centralized mechanism for all CBOs to obtain condoms free or at cost on a regular basis. HAA staff indicates that all HAA prevention grantees receive a budgeted amount for the purchase of condoms.[289] In addition, HAA staff reports that any provider or agency working with infected or at risk populations also can get condoms from HAA.[290] CBOs have reported difficulty obtaining condoms and female condoms from HAA on a regular basis, however.[291] Information on the availability of condoms to CBOs is not clear. HAA should have a mechanism for CBOs and other District agencies to order free condoms through HAA's website. New York City's Bureau of HIV/AIDS allows CBOs to order up to 10,000 condoms at a time at no cost through the Bureau's website.[292] When New York recently expanded its condom distribution program, Ansell Healthcare, the manufacturer of Lifestyles® condoms, donated 100,000 condoms to the city's efforts.[293] A representative from a major condom manufacturer indicated that HAA could negotiate for discounted prices on bulk purchases of condoms,[294] thus maximizing the use of available funds. Furthermore, the District may be able to obtain a large quantity of free condoms from a manufacturer, as did New York.

In addition to improving coordination with CBOs, HAA should coordinate with other District agencies providing services to high-risk populations, such as APRA, DMH, and DOC, to ensure regular condom distribution. Some mental health providers reported high demand among clients when free condoms are made available.[295] Since there is no regular distribution of condoms to other agencies and no easily identifiable mechanism for individual providers to order condoms directly from HAA, this demand is not regularly met.

SEXUALLY TRANSMITTED DISEASE PREVENTION AND TREATMENT

The STD Division of the DOH offers testing, treatment, outreach, education, and surveillance services.[296] The STD Division also provides technical assistance, training, and free testing supplies to local organizations, universities, and clinics that provide STD prevention and care services to District residents.[297] Outreach and education are provided through community health fairs, training for health care workers and counselors, and STD prevention workshops with DCPS students and community groups.[298]

The DOH's STD Clinic is the only publicly-funded clinic in the District. The clinic provides free STD screening, treatment, and referrals to all District residents.[299] Because the STD Division does significant HIV screening at the Clinic, HAA funds 11 of the STD Division's positions.[300] The STD Clinic is located on the grounds of the former D.C. General Hospital and can be difficult to find for those who are not already familiar with its location. The STD Division should promptly publicize the Clinic's services and location. In addition, DOH should evaluate the need to extend hours and increase the number of service locations.

According to STD Clinic staff, HIV testing is routinely offered at the Clinic.[301] However, HIV testing is conducted on an opt-in basis in which the client is asked if he or she would like to be tested. Yet, as discussed previously, an opt-*out* approach has been found to be more effective at increasing the number of clients who are tested. In fact, syphilis testing is conducted at the STD Clinic on an opt-out basis in which the client is informed that the test will be performed unless the client declines. The STD Clinic should take steps to ensure that HIV testing is conducted on an opt-out basis.

Rapid testing currently is not offered at the Clinic, and clients must wait two weeks to receive results. As discussed, the two-week wait often can lead to clients not returning for their test results. The STD Division reports that rapid testing will be implemented at the STD Clinic by the summer of 2005. The STD Division should implement rapid testing as soon as possible, particularly since, as explained previously, rapid HIV testing is less expensive than traditional HIV testing.

The STD Clinic also provides a key opportunity for clients to receive prevention education regarding STDs and HIV. The Clinic should ensure that all Clinic clients receive

counseling regarding STD and HIV prevention.

PREVENTION CASE MANAGEMENT

The District uses CDC funds to support a prevention case management program that targets high-risk groups.[302] This prevention case management program, however, needs improvement in training and coordination.

TRAINING FOR PREVENTION CASE MANAGERS

Under the CDC's guidance standards, prevention case managers must be provided opportunities for regular training and development.[303] In accordance with these standards, the 2003-2004 HIV Prevention Plan stated that HAA would provide training on behavioral and social interventions to CBO staff through CDC-funded training centers.[304]

In mid-2004, HAA reported to the CDC that HAA's attempts to provide training on HIV/STD prevention through the CDC-funded regional training centers had "proved difficulty [sic] because of the long lead time needed by these organizations and lack of funding to fund the training activities when their CDC funding had run out."[305] HAA also reported that "for small and new CBOs the scheduling of staff away from their agency for training strained service provision."[306] HAA should provide regular, ongoing training for prevention case managers. CBOs should participate in available training opportunities and coordinate scheduling with HAA.

COORDINATION OF PREVENTION CASE MANAGERS WITH RYAN WHITE CASE MANAGERS

To avoid duplication of services, the CDC recommends that prevention case managers and Ryan White case managers establish explicit relationships for coordination and/or integration of services.[307] Together, a Ryan White case manager and a prevention case manager can determine which services each should provide.[308] The Case Management Operating Committee, which will be described in Chapter VI, may be the most efficient way for the two types of case managers to coordinate their operations.

SUMMARY OF RECOMMENDATIONS

Routine Testing. The District should develop a city-wide strategy for implementing routine testing. HAA should expedite revisions of the HIV testing policy for pregnant women to adopt explicitly an opt-out approach. Routine testing also should be implemented by District agencies serving high-risk populations such as the STD Clinic, the TB Clinic, and APRA detoxification and substance abuse treatment centers. DOH and HAA should promote routine HIV screening by private doctors and medical facilities and provide pertinent information for effective test counseling. In addition, MAA and HCSNA should require providers to offer routine HIV testing to the District's Medicaid beneficiaries and Alliance enrollees.

Rapid Testing. HAA should expedite the implementation of rapid HIV testing at all District facilities, including the STD Clinic, APRA sites, the TB Clinic, and the D.C. Jail. In addition, HAA should provide training so that all CBOs may implement rapid testing. HAA also should coordinate with DMH in order to implement rapid testing at DMH-funded providers and St. Elizabeths Hospital.

Condom Distribution. HAA should significantly expand condom distribution efforts in the District. Condoms should be provided regularly in a variety of venues. Furthermore, HAA should develop centralized mechanisms for all providers of HIV/AIDS services and other District agencies to obtain free condoms. HAA should also coordinate with other District Agencies providing services to high-risk populations, such as APRA and DMH, to ensure regular condom distribution to their providers and clientele.

STD Prevention. The STD Clinic should ensure that all clients receive counseling regarding STD and HIV prevention. DOH should publicize the available services and location of the STD Clinic. In addition, DOH should evaluate the need for extended hours and additional locations for the STD Clinic.

Prevention Case Management. HAA should ensure that prevention case managers receive adequate specialized training on a regular basis. HAA also should develop a system for providing

better coordination between prevention case managers and Ryan White case managers.

CONCLUSION

The District should adopt a more comprehensive prevention plan to address the HIV/AIDS epidemic. As will be discussed in further detail later in this report, the District also should increase and strengthen existing prevention interventions with substance abusers, youth in D.C. Public Schools, and the incarcerated.

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PART 2: CHAPTER VI

HIV/AIDS TREATMENT AND CARE

CHAPTER INFORMATION:

Many people living with HIV/AIDS struggle with multiple needs. Proper health care, housing, food, income, and transportation are necessary to effectively manage and treat their disease. However, substance use and addiction, mental health problems, limited access to health care and support services, and poverty often result in these needs being unmet. Results from a 1996-1997 study found that more than one-third of people studied living with HIV delayed or did not obtain medical care because of other needs, including food, clothing, and housing, or barriers such as transportation, employment obligations, or severe illness.[309] Low-income persons have less access to health care and, perhaps as a consequence, may have poor health outcomes.[310]

This chapter describes the treatment and care required by individuals living with HIV/AIDS and the types of services provided by the District. Because individuals living with HIV/AIDS often face multiple health challenges, this chapter recommends greater coordination of treatment and care and augmented case management services.

BACKGROUND

HEALTH CARE NEEDS

The health care needs of an individual living with HIV/AIDS can be complex and may require a wide variety of services and care. The existence of comorbidities such as substance abuse, mental illness, Hepatitis C, and TB are complicating factors in the treatment of individuals with HIV/AIDS.[311]

MEDICAL CARE

Persons living with HIV/AIDS must receive comprehensive medical care to manage and monitor both health complications directly associated with HIV/AIDS or antiretroviral medications, as well as other concurrent medical conditions.[312] Patients with HIV/AIDS generally require more extensive medical screenings, examinations, and monitoring, particularly those taking medications to treat complications stemming from HIV/AIDS.[313] The medical provider coordinates a patient's treatment, including any necessary referrals to specialists, and ensures continuity of care.[314] In addition, the medical provider should educate the patient about HIV/AIDS and how to reduce the risk of transmitting HIV to others.[315]

Given the social, economic, cultural, and psychological challenges associated with HIV/AIDS, medical care for persons with HIV/AIDS can be extremely complex. In the most successful treatment relationships, doctors must be aware of existing resources in the community in order to make appropriate referrals for their patients and must work to develop a strong patient-doctor relationship in which confidentiality and cultural competence are present.

PRESCRIPTION DRUGS

People with HIV/AIDS need a variety of drugs to treat the disease itself and associated comorbidities, side effects, and opportunistic infections. The cost of antiretroviral drug therapy alone can be more than $12,000 per year for a single patient, not including the cost of medication for other opportunistic infections or side effects.[316]

When the HIV/AIDS epidemic was first recognized in 1981, patients diagnosed with AIDS typically lived for one or two years with

limited treatment options.[317] As mentioned previously, the picture of the HIV/AIDS epidemic changed dramatically in 1996, with the introduction of HAART.[318] HAART often reduces viral loads, which can help slow transmission, lengthen the time to the onset of AIDS, and increase life expectancy.[319] HAART can be effective in the treatment of individuals who have HIV as well as those who have developed AIDS.[320] Many experts believe that the introduction of HAART therapy played a critical role in reducing the AIDS death rate in the United States.[321] In 1997 alone, the AIDS death rate in the U.S. dropped 47 percent.[322]

Despite the positive impact on the life expectancy of those with HIV, HAART can cause severe side effects, including neurological disturbances, dizziness, fatigue, weight gain, skin rashes, nausea, diarrhea, and lack of appetite.[323] The severity of side effects and depression often are major factors in the failure of patients to adhere to drug therapy regimens.[324] When associated with other needed medications, HAART also can require administration of more than 20 assorted pills per day on an often-complicated schedule, which makes adherence difficult.[325] New regimens have been and continue to be developed that require fewer pills and less frequent dosing.[326]

Unfortunately, poor adherence to antiretroviral drug regimens can be particularly problematic. HIV develops resistance to drugs very rapidly. It is suggested that 95 percent or greater adherence is required to maximize the effectiveness of drug treatment, and studies have shown a marked increase in the development of drug resistance when adherence drops below 90 percent.[327] If antiretrovirals are not taken according to their precise instructions, the virus has more opportunities to replicate, thus increasing the likelihood that a random mutation will result in a resistant form of HIV.[328] As the virus becomes resistant to more types of antiretroviral drugs, treatment options are reduced.[329] Although critical to the therapy's success, strict adherence to a complicated medication schedule is extremely difficult.

Factors with a negative impact on adherence to drug therapy:

- Lack of education about HIV disease
- Denial, anxiety, or depression
- Alcohol or drug use
- Poor social situation
- Inadequate health insurance
- Number of medications or pills
- Frequency of dosing
- Stringent dosing requirements
- Presence of side effects
- Poor clinician-patient relationship

Judith A. Aberg et al., *Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: Recommendations of the HIV Medicine Association of the Infectious Disease Society of America*, 39 CLINICAL INFECTIOUS DISEASES 609, 609 (2004).

COMORBIDITIES

Comorbidity refers to the existence of one or more chronic conditions in addition to a primary disease. Comorbidities frequently occur in people with HIV/AIDS and may complicate their treatment or hasten the progression of the disease.[330] For example, drug interactions may occur among multiple medications used to treat several diseases and conditions.[331] Common comorbidities include:

SUBSTANCE ABUSE

As will be discussed in Chapter VIII, substance abuse is an important factor in the transmission of HIV and can be a serious obstacle to receiving proper health care. The DOH estimates that more than one-third of reported AIDS cases in the District have been linked to substance abuse.[332] An HIV-positive person with a substance abuse problem requires comprehensive treatment and care that addresses both conditions. Active drug or alcohol abuse may decrease an individual's adherence to drug therapy.[333] Drug or alcohol abuse also can impact an individual's general health and ability to receive proper treatment.

MENTAL ILLNESS

Many individuals living with HIV/AIDS also suffer from mental illness. Nationally, an

estimated 50 percent of those in HIV/AIDS care have some form of mental illness.[334]

Individuals with persistent or severe mental illnesses may be at increased risk for HIV. The mentally ill are generally more likely to engage in high-risk sexual activity such as unprotected sex, having multiple partners, buying and selling sex, and failing to learn the sexual history of their partners.[335]

Mental illness not only affects the transmission of HIV but may also hinder access to health care required by individuals living with HIV/AIDS.[336] Treatment of the underlying mental illness is an important precursor to successful HIV/AIDS treatment: if an individual is receiving treatment for mental illness, adherence to HIV/AIDS medication is more likely.[337] HIV-positive individuals taking medication for a mental illness must be properly monitored, because serious depression or other mental health disorders may be exacerbated by certain medications for HIV/AIDS.[338]

HEPATITIS C

Hepatitis C virus is a common comorbidity for those infected with HIV.[339] Hepatitis C can be transmitted through bodily fluids and blood (typically through injection drug use) and can lead to cirrhosis (liver scarring), liver failure, liver cancer, and death.[340] As many as 40 percent of all people living with HIV/AIDS may also be infected with Hepatitis C.[341] Among HIV-positive IDUs, the prevalence of Hepatitis C ranges between 50 percent and 90 percent.[342]

Hepatitis C-induced liver disease can be progressive, with cirrhosis developing in 20 percent to 30 percent of individuals.[343] In individuals co-infected with HIV, Hepatitis C progresses more rapidly and there is a higher prevalence of cirrhosis.[344] Also, the interval between Hepatitis C infection and cirrhosis is significantly shorter for individuals infected with HIV.[345] Recent studies also have reported that Hepatitis C infection might accelerate the progression of HIV to AIDS, but the evidence is not conclusive.[346] A common and very challenging consequence of Hepatitis C co-infection is the inability to tolerate certain HIV/AIDS medications because of the potential for liver toxicity.[347] Because of these concerns, HIV/AIDS medications should be administered cautiously, and liver function tests must be conducted in all patients co-infected with Hepatitis C.[348]

TUBERCULOSIS

HIV infection suppresses the body's immune system, increasing an HIV-positive person's risk of developing TB. An HIV-positive individual who contracts TB is 100 times more likely to develop active TB than a TB-infected person who does not have HIV.[349] Drug interactions also are a problem for the treatment of people co-infected with HIV and TB, and patients often experience adverse reactions because the preferred treatments of each disorder may not be compatible.[350]

OTHER NEEDS

In addition to proper treatment, sufficient nutrition, transportation, housing, and income are critical to effectively managing HIV/AIDS and maintaining optimal health. For a person living with HIV/AIDS, poor nutrition may result in increased vulnerability to opportunistic infections.[351] Poor nutrition also can have a negative impact on medication efficacy and adherence, ultimately accelerating the progression of HIV to AIDS.[352] Reliable transportation is necessary to enable people with HIV/AIDS to regularly access proper health care. Stable housing has been found to promote improved health status, sobriety, or decreased use of nonprescription drugs, and the potential for people living with HIV/AIDS to return to work.[353] Recent studies have also found that access to stable housing increases the ability of a person with HIV/AIDS to access comprehensive health care and adhere to complex HIV/AIDS drug therapies.[354]

However, because a significant number of HIV-positive individuals have limited financial resources, many important needs may not be met. Sufficient income support is an important resource for many people infected with HIV or living with AIDS. Low-income individuals living with HIV/AIDS may qualify for direct monetary assistance, food stamps, and health insurance. People with HIV/AIDS may also qualify for disability benefits from the Social Security Administration. The District also provides some transportation services to people living with HIV/AIDS.[355] In addition, HOPWA funding is available for housing-related assistance.[356]

CASE MANAGEMENT

As discussed above, persons with HIV/AIDS typically have complex health and social needs during the course of their illness. Case management is a service that keeps persons with HIV/AIDS linked to a continuum of health, mental health, social, and educational services and therefore assists in their ability to function independently with an improved quality of life.[357] Because of the multiple challenges faced by persons living with HIV/AIDS, the case manager must possess skills and a knowledge base that encompasses sensitivity to the psychosocial issues of drug use, chronic illness, poverty, and discrimination.[358]

HIV-positive individuals who have case managers have been shown to be more likely to take their antiretroviral medication and to obtain the necessary income support, health insurance, home health care, and counseling than those who lack case managers.[359]

HIV/AIDS case management services are provided by many different types of CBOs in the District and are supported by several funding streams, including Ryan White, SAMHSA, HOPWA, and CDC.

CASE MANAGEMENT OPERATING COMMITTEE (CMOC)

The CMOC was created several years ago by a group of approximately six case managers who received Ryan White funding.[360] The impetus for the CMOC was the perceived need among this small group of case managers for peer support.[361] Over the years, as HAA began funding larger numbers of case managers, HAA began to provide logistical support for the CMOC and made attending CMOC meetings mandatory for certain case managers.[362]

Representatives of the various HIV/AIDS case management organizations funded by Ryan White in the District currently participate in the CMOC. The CMOC meets monthly to address issues such as coordination and duplication of case management efforts, assessment of changing needs within the HIV/AIDS community, and discussion of policy and practice issues.[363]

CASE MANAGEMENT QUALITY ASSURANCE PROTOCOL

In an effort to improve case management service delivery throughout the District, the CMOC created a Quality Assurance subcommittee to improve and amend the Case Management Protocol used by HIV/AIDS case management agencies funded by Ryan White. This protocol is the result of "best practice" standards gathered from a variety of HIV/AIDS service providers throughout the United States.[364] The purpose of the protocol, which is now complete, is to provide a guide to ensure quality HIV/AIDS case management services throughout the District.[365] HAA recently approved the protocol, and some Ryan White case managers will be required to follow the protocol as part of their grant agreements once the Ryan White Planning Council approves the protocol.[366]

TRAINING FOR CASE MANAGERS

Special training and experience is required to become a successful HIV/AIDS case manager.[367] Case managers need to be up to date on changes in available services, the increasing complexity of the needs of persons living with HIV/AIDS, and the range of resources available to meet those needs.[368] In addition, they may need additional training to work with client populations that are new to them or have special needs, or to sharpen particular case management skills.[369]

FINDINGS AND RECOMMENDATIONS

COMORBIDITIES

MENTAL ILLNESS

Nationally, an estimated 50 percent of patients receiving HIV/AIDS care also suffer from some form of mental illness.[370] Currently, the comorbidity rate in the District is unknown, and the District currently has no mechanism to track the number of dually-diagnosed residents. Such data are necessary to formulate effective prevention

interventions and also to appropriately allocate resources for care.

A significant barrier to serving the dually diagnosed in the District is the lack of coordination between HAA and DMH. Increased cooperation is imperative to connect DMH clients with available HIV/AIDS resources, such as HIV/AIDS medications through ADAP.[371] Mental health providers in the District also have reported difficulties obtaining adequate specialized HIV/AIDS training for their clinical staff.[372] Such training should be made available to all mental health providers. HAA and DMH should collaborate to develop training materials regarding HIV/AIDS and the complexities involved in treating people with HIV/AIDS and mental health disorders.

There also is a need for additional collaboration between HAA and mental health providers regarding prevention services, including HIV counseling and testing. Because mental health providers often have regular contact with their clients, such providers may have a good opportunity to provide these services. In addition, the community-based mental health centers can be a vehicle for other prevention efforts such as the distribution of condoms, as discussed in Chapter V, and educational materials. Two mental health providers noted a high demand for condoms and educational materials among their clients.[373] HAA should coordinate with DMH or directly with mental health providers to ensure the availability of condoms and educational materials at mental health treatment sites. Condom distribution and associated costs were addressed in Chapter V.

TUBERCULOSIS

CDC Guidelines for HIV testing recommend that HIV testing and counseling be provided for those who are confirmed or suspected of having TB, and that HIV testing be made available on site at all TB clinics.[374] However, it is unclear whether this actually occurs in the District. A clinician at the District TB Clinic reported that if an individual has active TB,[375] he or she will receive an HIV test; however, it could not be confirmed whether this is universally followed at the clinic or whether this is a DOH policy. Furthermore, the clinician indicated that HIV testing was not performed for those who have been exposed to TB but are not found to have active TB. DOH should develop and enforce a policy that all individuals who test positive for TB exposure or active TB at the District TB Clinic should be tested for HIV. The cost-effectiveness of routine testing was discussed in Chapter V.

In terms of surveillance, the District does not compile statistics on the prevalence of people living with both TB and HIV/AIDS. According to the CDC, the District reported TB rates above the national average (5.1 cases per 100,000 population) in 2003.[376] Specifically, there were 79 reported cases of TB in 2003, 82 in 2002, and 74 in 2001.[377] The prevalence of people with HIV/AIDS and TB can only be estimated. CDC's minimum estimate of HIV co-infection in 1998-1999 was approximately 10 percent of all persons with TB.[378]

OTHER NEEDS

DC Appleseed did not evaluate the efficacy of food, transportation, housing, or other supplemental programs. Thorough evaluation of these programs' ability to meet District needs may be necessary, particularly regarding housing.

Many persons living with HIV/AIDS, as well as providers, cited housing shortages as a major challenge in the District. Housing is a serious concern in the District due to a severe shortage of affordable housing for low-income people generally. In the District, most of the housing units set aside for individuals living with HIV/AIDS are transitional.[379] Transitional housing often is limited to two years and typically has strict restrictions on tenant behavior, such as sobriety requirements.[380] Yet, even these transitional units are available only in limited numbers.[381] In general, there continues to be a shortage of housing providers for those living with HIV/AIDS.[382]

Grant processing and reimbursement delays have been cited by some providers as the major challenges in addressing the housing shortage. Other comparable jurisdictions have been able to provide for the housing needs of persons living with HIV/AIDS in their communities through a variety of means, including: legislated mandates requiring immediate housing placement for

all persons with HIV/AIDS; specific local and federal funding allocation schemes for housing development and subsidies; comprehensive financial planning with housing providers; and the coordination of strong relationships with developers and local banks.[383] Such initiatives may be appropriate in the District to address the housing needs of persons with HIV/AIDS.

CASE MANAGEMENT

TRAINING FOR CASE MANAGERS

Case managers report that they do not receive enough professional and in-service training.[384] Currently, the Quality Assurance subcommittee of the CMOC provides training for members of the CMOC, with logistical support from HAA.[385] But, as noted, the CMOC does not include all case managers. HAA should provide (or contract a third-party to provide) regular training for all of the District's HIV/AIDS case managers, in coordination with the QA subcommittee of the CMOC or a new Needs Assessment subcommittee. To guide the specific training offered by HAA, members of the CMOC and HAA should conduct an annual assessment of training needs of case management staff. This process also should be informed by client satisfaction surveys in order to identify areas in which additional training is needed. Finally, HAA should include training requirements in grants with a case management component.

Some jurisdictions partner with local universities and nonprofit organizations that have expertise in case management to ensure that their HIV case managers receive adequate training. For example, case managers in New York and New Jersey have access to training and HIV case management certification programs at Columbia University's Mailman School of Public Health and the University of Medicine and Dentistry of New Jersey.[386] The District should explore partnering with a local university or organization to provide training for case managers.

FUNDING

Currently, case management is funded through Ryan White, but it should be added to the Medicaid benefits package so that providers can bill Medicaid for case management services provided to Medicaid beneficiaries, reducing the strain on Ryan White resources. The District has several options for adding case management services to its Medicaid benefits package. First, the District could receive its regular federal match by amending its State Plan to include case management services for all beneficiaries. Alternatively, it could amend the plan to target the services to specific beneficiaries or providers. Third, the District could count the costs of case management services under its administrative budget and receive only a 50 percent match from the federal government. By adding case management services to the Medicaid package, the District would increase the availability of Ryan White funding for other services.

The District currently provides case management services to individuals enrolled through the Ticket to Work and the Medicaid Section 1115 waiver. The District's 1915(c) waiver could be amended to provide case management services. As of November 2003, five states had requested or had received approval for 1915(c) waivers to provide case management services to Medicaid-eligible persons with HIV or AIDS.[387]

SUMMARY OF RECOMMENDATIONS

Comorbidities. DOH should work to identify and target people with comorbidities for testing, treatment, and care. DOH also should improve the availability of data regarding comorbidities. HAA and DMH should collaborate to provide adequate training on HIV/AIDS issues to mental health workers. HAA also should facilitate prevention interventions, including testing and counseling, education, and condom distribution for the mentally ill at mental health provider sites and St. Elizabeths Hospital. DOH should implement and enforce a policy that all individuals who test positive for TB exposure at the District TB Clinic or who have active TB be tested routinely for HIV. HAA also should increase interagency collaboration to improve

treatment and care for other comorbidities such as substance abuse and Hepatitis C.

Case Management. HAA should monitor adherence to revised case management protocols and provide case managers with regular substantive training and current information about available resources and services for their clients. The District should expand Medicaid benefits to include case management, allowing providers to better maximize Ryan White funding.

CONCLUSION

People living with HIV/AIDS, particularly those with comorbidities, have complex needs that require comprehensive health care, case management services, housing assistance, and, often, food, income maintenance, and transportation assistance. Because various agencies in the District oversee the provision of these services, systematic interagency collaboration is needed.

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PART 2: CHAPTER VII

HIV PREVENTION IN D.C. PUBLIC SCHOOLS

CHAPTER INFORMATION:

Many young people have misconceptions about the health risks associated with HIV/AIDS and have incomplete information on the methods of protecting themselves and the need for testing. As will be discussed, youth in the District face serious risk of HIV infection due to above-average rates of unprotected sex and substance use. Therefore, a targeted and comprehensive HIV prevention program is imperative to provide young people in the District with the skills and information to protect themselves. Schools have the opportunity – and the responsibility – to provide age-appropriate HIV prevention education and support to students.

This chapter will describe the HIV prevention programs that exist within the D.C. Public Schools (DCPS). This chapter recommends the development and implementation of comprehensive standards for HIV/AIDS education in the schools, evaluation of HIV/AIDS education services, improved collection of data on HIV/AIDS services in the schools, better coordination of HIV/AIDS services within DCPS' administrative offices, and expanded communication with the public and other agencies regarding DCPS HIV/AIDS' program.

HIV/AIDS AMONG YOUTH

More than a quarter of Americans living with HIV/AIDS became infected during their teen years.[388] It is estimated that 50 percent of new HIV infections in the United States occur in individuals under the age of 25.[389] According to the District's 2004 Ryan White Title I grant application, an estimated 2,242 youth are infected with HIV in the Washington, D.C. Eligible Metropolitan Area.[390]

The 2003 Youth Risk Behavior Survey (YRBS) data indicated a decrease in the number of District students that report having sex.[391] However, youth in the District continue to report sexual and high-risk behavior at higher rates than national averages.[392] According to 2003 YRBS data for the District:

- 64 percent of District students reported having sexual intercourse at least once (47 percent in U.S.);
- 45 percent of District students reported having sexual intercourse with one or more people during the past three months – of those, 19 percent reported having had sexual intercourse under the influence of alcohol or drugs (34 percent and 25 percent in U.S.);
- 25 percent of District students had sexual intercourse with four or more people during their life (14 percent in U.S.).[393]

In 2000, the District's pregnancy rate was 128 pregnancies per 1,000 women of 15 to 19 years of age, higher than any state (the national average was 84 pregnancies per 1,000).[394] The CDC's 2003 STD Surveillance Report indicates that the District's STD rates also are significantly higher than the national averages. The national rate for gonorrhea in 2003 was 116 reported cases per 100,000 of the civilian population.[395] The District's rate was 439 cases per 100,000, almost four times the national average.[396] Similarly, in 2003, the rate for chlamydia in the District was almost twice the national average (555 per 100,000 in the District as compared to 304 per 100,000 nationally), and the rate for primary and secondary syphilis cases was more than three times the national average (8.4 per 100,000 in the District as compared to 2.5 per 100,000 nationally).[397] In the

District in 2003, a total of 2,041 new cases of chlamydia, gonorrhea, and syphilis were diagnosed in persons under the age of 20.[398] The previous year, youth under the age of 20 accounted for 38 percent of all new cases of chlamydia, 24 percent of new gonorrhea infections, and 7 percent of new syphilis cases in the District.[399]

As noted previously, substance use contributes to the risk of HIV and STD transmission, either because of transmission via infected syringes, or because the influence of drugs and alcohol increases the likelihood of unprotected sex. Among youth surveyed for the 1997 District of Columbia Youth Behavioral Risk Factor Survey, 71 percent reported drinking alcohol, 52 percent had used marijuana, and 25 percent had obtained an illegal drug on school property.[400] According to 2003 YRBS data, 3.9 percent of District youth surveyed reported injection drug use during their lifetime, which is comparable to the national median of 3.2 percent.[401] Further, 5.4 percent of District students reported using heroin at least once in their lifetimes, as opposed to 3.3 percent of students nationwide.[402]

HIV PREVENTION IN DCPS

As with other aspects of HIV prevention, CDC provides funds and general guidance to school districts to combat the spread of HIV. CDC does not specify how schools should use the funds; rather, the agency allows schools to create their own HIV prevention programs to specifically appeal to their target audience, consistent with local community and parental values.[403] Given the topic's sensitivity, the CDC recommends that schools develop HIV/AIDS education programs with participation from a wide range of community groups.

DCPS serves approximately 65,000 students who attend 167 D.C. public schools and 14,000 who attend roughly 46 D.C. public charter schools. A number of HIV prevention programs directly targeting students in the DCPS are described below.

These programs are administered primarily through three offices within DCPS' central administration which provide HIV/AIDS services to DCPS students and schools.

THE HIV/AIDS EDUCATION PROGRAM

The HIV/AIDS Education Program is funded directly by the CDC Division of Adolescent School Health (DASH) and receives no local funding from DCPS or HAA. In fiscal year 2005, DCPS received $249,936 from the CDC for the HIV/AIDS Education Program. The same amount is projected for fiscal year 2006.[404] While DCPS does not provide any local funding for this program, it does provide funding for the other offices described below. The HIV/AIDS Education Program serves all District public schools and is located at an elementary school in Southeast D.C. This office provides technical assistance in planning, developing, and implementing HIV/AIDS prevention programming in schools. According to DCPS' DASH grant proposal, the office provides professional development to teachers in the use of CDC-approved HIV/AIDS curricula and limited training to CBOs. This office also works with Children's National Medical Center (CNMC) and the school nurses on the Adolescent AIDS Prevention Program, described below. Formerly, in the absence of a Health and Physical Education Director, this office helped to coordinate access to schools for CBOs wishing to provide HIV/AIDS services.

HEALTH AND PHYSICAL EDUCATION

The Health and Physical Education Director for DCPS is responsible for system-wide instruction in health and physical education. In general, the Health and Physical Education Director's primary responsibilities are to develop curricula, train teachers, and provide other technical assistance to schools. The Health and Physical Education Director works closely with the HIV/AIDS Education Program to provide training to teachers in the use of CDC-approved curricula. This position had been vacant for about one year before it was filled in April 2004.

SCHOOL HEALTH PROGRAMS

The Director of School Health Programs is DCPS' liaison for the CNMC School Nursing

program. She is responsible for ensuring policy compliance. This includes monitoring the policies and procedures of school health programs, coordinating health services and systems to meet compliance standards, and organizing technical assistance based on federal and District school health regulations.

The Adolescent AIDS Prevention Program was created in 1992. Since 2001, this program has been managed by the CNMC. The steering committee for this endeavor consists of nurses, parent groups, clergy, public school administrators, and D.C. Council members. An important part of this program involves condom distribution. At any time during the school year, a high school student may obtain condoms from a nurse once the student has received counseling and instructions on condom use (on subsequent visits, the student is permitted to obtain condoms without further counseling).[405]

COMPONENTS OF A SUCCESSFUL HIV PREVENTION PROGRAM

In general, a successful HIV prevention program for youth will have four components: (1) a curriculum that meets community needs and standards; (2) professional development for instructors that is updated regularly to reflect advancements in HIV knowledge and prevention strategies; (3) collaboration with other agencies and community organizations; and (4) monitoring and evaluation of program impact.[406] DC Appleseed found major impediments to each component in DCPS' HIV prevention programming, which leaves young people in the District vulnerable to HIV and other sexually transmitted infections.

CURRICULUM

DCPS is highly decentralized. Principals must meet standards and graduation requirements but otherwise have a great deal of control over what is taught in their schools and which staff positions are filled. Thus, DCPS lacks a standardized curriculum that is implemented uniformly in all schools (although the Health and Physical Education Director hopes to establish such a curriculum). Instead, school health courses are expected to meet standards set by the American Association of Health Education. Teachers have been trained in the use of the association's standards; however, the school system will not formally adopt them until later in 2005.[407] DCPS students are required to take Health and Physical Education through the 10th grade, but school principals may choose the degree to which HIV prevention is addressed. In fact, not all schools have a health or physical education instructor.

The District regulations require "health instruction within a planned, sequential, pre-K-12 comprehensive school health education curriculum."[408] Comprehensive school health education is defined as "age appropriate instruction that improves the knowledge, skills, and behaviors of students so they choose a health-enhancing lifestyle and avoid behaviors that may jeopardize their immediate or long-term health status."[409] Health instruction must include information about HIV/AIDS and STDs, as well as human sexuality.[410] However, there currently are no system-wide standards or mandates for HIV/AIDS education at particular grade-levels, no tracking of HIV/AIDS education received by students, and no standards for the quality of education they received.

Some schools, but not all, work with CBOs, which provide various curricula. CBOs that are approved by the HIV/AIDS Education Program or that receive federal funding use CDC-approved curricula.[411] CDC-approved curricula are all multi-session workshops with informational as well as skills-building components. The CDC's guidelines on effective HIV-prevention education emphasize age-appropriate, comprehensive curricula that help students understand "the relationships between personal behavior and health."[412] CDC-approved curricula include information on abstinence, HIV/AIDS prevention through condom use, as well as information about transmission through substance abuse. However, some CBOs – that have not received approval through the HIV/AIDS Education Program – have provided "one-shot" HIV prevention sessions, often simply providing PowerPoint presentations,

to students.[413] As will be discussed, DCPS lacks clear, consistently applied standards for the programs operating in its schools.

PROFESSIONAL DEVELOPMENT

The Director of the HIV/AIDS Education Program provides training for health education teachers for credit toward graduate and recertification requirements. This training is voluntary, and thus only a small number of teachers participate. Furthermore, the teachers who choose to participate may not be the ones in greatest need of training.

Training for principals also is voluntary. DCPS' administrators have expressed concerns about the manner in which some principals treat HIV-positive students. In addition, school staff lacks information about accessing social services for these students and their families.[414]

COLLABORATION AND COORDINATION

The schools, the nurses, and the CBOs have all expressed the need for better collaboration and coordination.[415] CBOs have repeatedly encountered difficulty "getting into the schools." Some felt they were "not welcome" in the public schools and had to keep a low profile and work behind the scenes. CBO staff expressed that oftentimes it has been easier to work directly with a principal than to go through the HIV/AIDS Education Program. At the same time, it is understandable that DCPS would like all providers to go through a centralized office within DCPS, particularly given the sensitive nature of HIV prevention programs. DCPS administrators have expressed frustration that CBOs do not contact their office, but rather, go directly into a school through the principal, making it difficult to discern which schools have programs and which do not. One DCPS administrator suggested that CBOs need to be "less competitive" about getting into certain schools and more willing to work with the school system to ascertain the needs of all schools.

The Director of the HIV/AIDS Education Program has stated that the Program's responsibilities include working in partnership with CBOs to provide and enhance HIV/AIDS prevention programming in schools as well as to assist these organizations in gaining access to schools. Yet, all of the CBO directors interviewed for this report raised serious concerns about the performance of the HIV/AIDS Education Program office. In fact, one local CBO that has provided HIV prevention services in the schools for the last five years had not even heard of the office or its director. In an interview in fall 2004, the Director of the HIV/AIDS Education Program stated that she was informally responsible for coordinating access to schools with CBOs and that this process would be facilitated by a workshop conducted at the beginning of the academic year for all CBOs interested in working within schools. Later, she reported that this workshop did not occur and that responsibility for the workshop was moved to the office of the Health and Physical Education Director.

Currently, the responsibility for reaching out to CBOs, approving CBOs to work in schools (a new Memorandum of Understanding (MOU) process has been developed for this purpose), and developing standards for and monitoring CBO performance now falls to the Health and Physical Education Director. However, because the Director also is working on the development of new District-wide curriculum standards, it is questionable whether she will have time to adequately perform these additional responsibilities, and whether working with CBOs is an appropriate responsibility for this office.

At best, coordination of the various offices would be challenging given the organizational and physical placements of the three offices. The Health and Physical Education Director falls under the Curriculum Office of the Chief Academic Officer, while the Director of School Health and Director of the HIV/AIDS Education Program are under the supervision of the Assistant Superintendent for the Division of Student Affairs. The HIV/AIDS Education Program office is located at an elementary school in Southeast D.C., while the other two are at DCPS' central administration office.

DCPS policies regarding coordination between principals and the DCPS central administrative offices are also unclear. Principals answer to their Assistant Superintendent and are not accountable to the HIV/AIDS Education Program. They

are not required to report to the central administration what programs are being offered in their schools – thus, the school system may have no information about those programs.

In addition, despite the complicated structure of DCPS' HIV/AIDS services, the DCPS website offers no information about the services to the public other than a phone number in their office directory for the HIV/AIDS Education Program Office. As stated above, that office is no longer responsible for working with CBOs. A page listed as "Comprehensive Student Health Program"[416] says only that "this program coordinates health services in partnership with the Commission of Public Health and works with students, families, staff, community-based organizations, and universities." No contact information or other details are offered. In fact, the Commission of Public Health is no longer in existence (it is now the DOH).

According to the CDC, a coordinated school health program has nine components: health education, physical education, health services, nutrition, counseling, social services, healthy school environment, healthy staff, and family and community involvement.[417] HIV/AIDS education and services are an important part of a comprehensive health program. Yet, there is no indication that DCPS coordinates these nine components in a meaningful way.

MONITORING, DATA COLLECTION, AND EVALUATION

Limited data are available on DCPS HIV education programs and their impact on students. The HIV/AIDS Education Program provided some survey data regarding the content of required health education courses in grades 6-12. For example, 100 percent of teachers in required health education courses taught how HIV is transmitted and that abstinence is the most effective method to avoid HIV infection. In middle schools, 87 percent of teachers in required health courses taught students how to correctly use a condom.

However, the survey data provided by the HIV/AIDS Education Program merely report which topics were taught, without information on the quality of teaching, the duration of the lesson, or the degree to which the course influenced student behavior. There is no routine monitoring or evaluation of HIV prevention programs in the schools. Each provider evaluates its own programs, and there are no consistent standards by which to measure. Many CBOs evaluate their programs through the use of pre- and post-tests and surveys. Yet such evaluations are neither systemic (occurring in all programs on a regular basis, with data that can be compared across all programs) nor objective (results are collected and reported by each individual program so they are unlikely to be critical).

DCPS should do a better, more systematic job of collecting data on the HIV/AIDS education programs and services provided in its schools. At present, it is highly likely that some schools with the greatest need are completely without HIV prevention programs.

DCPS HIV/AIDS AD HOC COMMITTEE

In November 2004, in recognition of the urgent need for improvement in HIV prevention and sex education, the DCPS Board of Education created an Ad Hoc Committee. This Committee included the Superintendent, Board of Education members, representatives of the Mayor and Council, HAA officials, and representatives from other agencies and CBOs. The Committee, in which DC Appleseed also participated, met monthly to develop recommendations regarding the creation of comprehensive system-wide health and HIV/AIDS education standards and testing and treatment policies for DCPS youth. The Committee compared the District's health education policies with those of other jurisdictions and also considered national standards for health education.

At the final June 2005 meeting, the Committee presented its recommendations to the D.C. Board of Education. These recommendations addressed many of the concerns raised in this chapter. The Committee recommended updating both the D.C. Municipal Regulations and the Board of Education's HIV/AIDS policies, which were

last updated in 1994. The Superintendent and Board of Education will review the recommendations and determine the next steps. The Superintendent anticipates formally convening a similar committee of advocates and stakeholders in the fall.

SUMMARY OF RECOMMENDATIONS

Standards Regarding HIV/AIDS Education in the Schools. The Board of Education and DCPS should develop system-wide content standards regarding HIV/AIDS education. The Board of Education also should review and amend the outdated D.C. Municipal Regulations relating to HIV/AIDS in the school system and ensure that school staff is trained regarding these regulations.

Evaluation. In collaboration with CBOs, DCPS should develop standardized performance measures for HIV/AIDS education. These performance measures should be used to evaluate all schools and all HIV/AIDS services provided in public schools.

Data Collection. The District should establish guidelines and policies to improve collection of data regarding HIV/AIDS education programs and services in the schools. Principals should be required to report all HIV/AIDS service providers to the appropriate DCPS administrative office, so that DCPS may maintain an updated list of all HIV prevention programs in schools and ensure that all schools are providing adequate HIV/AIDS prevention services.

Improved Coordination. DCPS needs to better align the responsibilities of its offices that coordinate health policy and health education. DCPS should create a coordinated school health office that includes the liaison to the School Nursing Program, HIV/AIDS Education, and other health-related programs. In addition, DCPS should conduct a thorough evaluation of the functionality of the HIV/AIDS Education Program office.

Expand Public Communication and Involvement. The Board of Education should establish an "Advisory Council on Student and School Health" that would include participation from DOH, HAA, CNMC, CBOs, the D.C. Council and Mayor's Office, local children's health advocates, school nurses, parents, and national experts. DCPS also should improve communications with the public about DCPS' HIV/AIDS education program. One step would be to update the website to include detailed contact information, the roles of the different offices, the MOU policy for CBOs, and links to related agencies (e.g., DOH's Office of Maternal and Child Health and HAA). The website could provide links to data and research, and more importantly, where to obtain HIV testing, prevention, and care services.

CONCLUSION

DCPS is in the midst of overhauling its curriculum standards and implementing an ambitious new strategic plan, but HIV prevention is not receiving a great deal of attention from the administration. The Board of Education's recent efforts to focus on HIV/AIDS is a step in the right direction, but DCPS needs a coordinated and sustained effort to reduce the spread of HIV among the District's youth. DCPS also needs to give serious consideration to whether the current configuration of offices and responsibilities, as well as the distribution of resources, can be improved.

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PART 2: CHAPTER VIII

HIV PREVENTION AMONG DRUG USERS

CHAPTER INFORMATION:

Drug users are at increased risk for contracting HIV because they engage in high-risk drug and sexual behaviors. In the District, injection drug use is the second most common mode of transmission of HIV among men, and the most common mode of HIV transmission among women.[418] Almost a third of new AIDS cases in the District can be directly traced to a shared needle, and far more cases can be traced indirectly to drug use through sexual contact.[419]

HIV prevention efforts in the District targeting drug users and their sex partners should be enhanced. Research has shown that the most effective approach for preventing the spread of HIV among drug users is a comprehensive strategy that includes community-based outreach, drug abuse treatment, and syringe access.[420] Such programs should be combined with testing and counseling for HIV and strategies to prevent sexual transmission of HIV, such as distribution of condoms and educational material.

As this chapter describes in further detail, although the District currently employs multiple interventions targeting drug users, the District's efforts are inadequate. A coordinated, comprehensive approach is needed because no one intervention is effective on its own. This chapter recommends expanding substance abuse treatment services. In addition, HAA should ensure the provision of services to complement syringe exchange programs (SEPs), which have been demonstrated to be effective in reducing HIV transmission among injection drug users (IDUs). DOH also should improve collection and dissemination of data on substance abuse in the District.

DRUG USE AND HIV/AIDS

BACKGROUND ON DRUG USE AND HIV/AIDS

Drug addiction is a complex chronic disease characterized by compulsive, uncontrollable drug craving, seeking, and use, despite severe consequences.[421] Even many of those who seek and receive treatment often relapse.[422] Many IDUs are marginalized and cannot fully participate in the economic, social, or cultural life of their community. For those IDUs living with HIV/AIDS, the stigmatization and marginalization are likely to be greater.[423]

The process of injecting drugs and the sharing of equipment provide many opportunities for the transmission of HIV and other blood-borne viruses.[424] Sharing drug injection paraphernalia usually occurs because IDUs lack access to or cannot afford their own equipment.[425] In addition, high-risk drug use behaviors and high-risk sexual behaviors often are linked, further increasing the risk of HIV and other blood-borne diseases being transmitted from person to person. These risky sexual behaviors include unprotected sex and intercourse with multiple partners.[426]

Not all IDUs experience the same level of risk.[427] Research has shown that the relative socio-economic status of IDUs has a direct influence on the degree of risky behavior in which the IDU engages. IDUs who initially have higher socio-economic status, housing, and support networks may be more able to control their risks of transmission. Lower income IDUs, those with mental health problems, and those with unstable living and social circumstances may have difficulty obtaining sterile syringes and, thus, may be more likely to share injection equipment.[428] HIV prevention may not be the top concern for such persons, because they face other more pressing daily challenges such as addiction, poverty, incarceration, homelessness, stigma, mental illness, and past trauma.[429]

DRUG USE AND HIV/AIDS IN THE DISTRICT

In 2000, approximately 60,000 District residents – nearly one in 10 – were addicted to illicit drugs or alcohol.[430] Almost 10 percent of District residents reported illicit drug use in 2000, which was almost double the nationwide reported drug use rate of 6.3 percent for the same year.[431] Among District residents between the ages of 18 and 24, the rate of reported drug use was nearly 21 percent – meaning that one in five reported using illicit drugs within the past month.[432] In 2003, of those individuals admitted to substance abuse treatment, more than half reported heroin or cocaine as their drug of choice.[433]

There are an estimated 9,720 IDUs in the District.[434] However, this estimate is based on a survey that did not include the homeless, the incarcerated, or individuals in treatment facilities – populations that are known to have high numbers of IDUs.[435] Thus, the number of IDUs in the District is likely to be significantly higher.

HAA reports that, as of early 2005, 2,686 of the IDUs in the District are living with AIDS.[436] This is almost one-third of the estimated IDUs in the District. A significantly greater percentage of IDUs may be HIV-positive, but, as discussed in Chapter III, the District's HIV data, including data regarding IDUs, are unavailable.

HIV PREVENTION STRATEGIES FOR DRUG USERS

Prevention of HIV among drug users requires a comprehensive strategy that includes community-based outreach, drug abuse treatment, and syringe access programs. Without such a strategy, a substantial percentage of the District's population is at increased risk of contracting HIV. Each of these components is described below.

COMMUNITY-BASED OUTREACH

Drug use is usually a covert activity, making it difficult to reach drug users and their sex partners through traditional health and social service agencies.[437] To effectively provide prevention, treatment, and care services to IDUs, it is essential to bring the services to IDUs in the settings in which they live and socialize.[438] Outreach workers who are familiar with the drug use subcultures and local neighborhoods have been shown to be effective agents of behavioral change and referral sources to service agencies and substance abuse treatment facilities.[439]

A typical outreach encounter involves face-to-face communication that is intended to assist IDUs in changing their high-risk drug use and sexual behaviors. Outreach workers may distribute literature on drug use, substance abuse treatment, and HIV prevention, and they provide information on available services. They also distribute condoms and may help IDUs obtain housing assistance or mental health treatment. Outreach also involves working with drug users' social networks to extend and reinforce prevention messages and build risk-reduction skills.[440]

OUTREACH EFFORTS IN THE DISTRICT

Several District agencies and CBOs are involved in outreach efforts to District drug users. The District, through APRA, operates "Project Orion," a 34-foot mobile medical outreach unit targeting drug users.[441] Project Orion is funded with a grant from SAMSHA and is partnered with Unity Health Care, Inc. and HAA to provide targeted services to areas where addicts congregate. Project Orion provides primary medical care; case management; substance abuse education and counseling; and HIV, hepatitis, STD, and TB testing and counseling.[442] It also refers individuals to detoxification and substance abuse treatment programs and the First Street Health Center, which coordinates extensive chronic disease screening and treatment services for dually- and triply-diagnosed individuals.[443] First Street is jointly funded by HAA and APRA.[444] In addition to being a partner in the operation of Project Orion, HAA provides grants to two CBOs to conduct outreach to IDUs.[445] Other

organizations in the District conduct privately-funded outreach to drug users.

SUBSTANCE ABUSE TREATMENT

For IDUs, substance abuse treatment is a proven HIV prevention strategy. IDUs who do not enter treatment are up to six times more likely to become infected with HIV than IDUs who enter treatment and successfully avoid relapse.[446] Substance abuse treatment helps drug users reduce the number of drug injections and thus lower the risk of infection with HIV or hepatitis that might occur through unsafe injection practices.[447] Substance abuse treatment also provides the medical, psychological, and behavioral support to help individuals stop using drugs.[448] Further, because drug use impedes rational decision making, which can lead to high-risk behavior, substance abuse treatment can reduce the risk of HIV and hepatitis transmission through unprotected sex.[449]

Sustance abuse treatment for IDUs is important not only to prevent HIV, but also for HIV-positive IDUs. Continued drug or alcohol abuse can severely impact an individual's general health, which can accelerate the progression of HIV infection into AIDS. Chronic substance abuse also has been shown to decrease adherence to medical treatment for those who are HIV-positive.[450]

TREATMENT IN THE DISTRICT

Substance abuse treatment programs differ in their approaches and components. They are generally divided into five major kinds of programs: detoxification; inpatient; therapeutic communities; outpatient; and methadone or buprenorphine maintenance.[451]

According to the National Survey of Substance Abuse Treatment Services, 54 facilities in the District provide substance abuse treatment.[452] Although only one-third of these facilities reported that they provide special programs for persons with HIV/AIDS, nearly 80 percent reported that they provide HIV/AIDS education, counseling, and support. Only half of the facilities conduct testing for HIV, hepatitis, TB, and STDs.[453]

In 2001, D.C. Mayor Anthony Williams recognized the need for improved services for drug users and appointed the Mayor's Interagency Task Force on Substance Abuse Prevention, Treatment, & Control (Task Force) to recommend a citywide substance abuse strategy and budget. The Task Force found that the District has insufficient capacity to meet the demand for treatment services.[454] Although in 2002 there were an estimated 60,000 individuals with substance abuse problems in the District, only 8,500 individuals entered substance abuse treatment.[455] Although all substance abusers do not seek treatment, it is essential that the District expand treatment capacity.

The Task Force established a strategy, released in September 2003, which includes four goals: (1) "educate and empower District of Columbia residents to live healthy and drug-free lifestyles"; (2) "develop and maintain a continuum of care that is efficient, effective, and accessible to individuals needing substance abuse treatment"; (3) "increase the public's safety and improve treatment access for offenders to ensure fair and effective administration of justice in the District"; and (4) "encourage a coordinated and focused regional response to the problem of substance abuse."[456] To achieve these four goals, the Task Force identified policy and program priorities and set up a timeline and reporting procedures to track progress.

Although progress has been made, budget shortages have limited the District's ability to substantially improve substance abuse treatment.[457] The District's treatment capacity continues to be inadequate to meet the demand for services.[458] The District should continue to expand treatment services and periodically reevaluate capacity levels. Expansion of treatment capacity will require significant funding increases, but the District may be able to obtain additional grants from SAMSHA or other sources to cover this critical service.

ACCESS TO STERILE SYRINGES

IDUs who share drugs, syringes, and other injection equipment or who practice unsafe sex while under the influence of drugs are at high risk of contracting and spreading HIV and other infections.[459] Thus, public health

officials and substance abuse experts have recommended programs, such as SEPs, that mitigate the adverse consequences of injection drug use.[460] The most effective SEPs also provide complementary services such as HIV testing, counseling, and drug treatment referrals.

Several HIV prevention strategies are available to IDUs.[461] The National Institute on Drug Abuse of the National Institutes of Health describes these strategies in a "hierarchy of HIV/AIDS risk-reduction messages, beginning with the most effective behavioral changes that drug users can make:

- Stop using and injecting drugs.
- Enter and complete drug abuse treatment, including relapse prevention.
- If you continue to inject drugs, take the following steps to reduce personal and public health risks:
  - Never re-use or "share" syringes, water, or drug preparation equipment.
  - Use only sterile syringes obtained from a reliable source (e.g., a pharmacy or a syringe access program).
  - Always use a new, sterile syringe to prepare and inject drugs.
  - If possible, use sterile water to prepare drugs; otherwise use clean water from a reliable source (e.g., fresh tap water).
  - Always use a new or disinfected container ("cooker") and a new filter ("cotton") to prepare drugs.
  - Clean the injection site with a new alcohol swab before injecting drugs.
  - Safely dispose of syringes after one use."[462]

This hierarchy illustrates what has become known as "harm reduction" in the addiction community. The term "harm reduction" has various meanings, but it generally refers to methods of reducing risks to health where elimination of risk may not be possible.[463] As an addiction expert recently testified before Congress, "harm reduction efforts are not intended to make drug use 'safe'; rather, they seek to lessen the extraordinary suffering, death, and dissolution of family and communities with which addiction is associated."[464]

Indeed, the theory of harm reduction is standard practice when it comes to addiction treatment and HIV prevention. *A Guide to Primary Care of People with HIV/AIDS*, published by HHS, counsels: "The primary care provider should routinely screen for drug abuse and treat or refer for treatment as quickly as possible . . . [and] the provider should also counsel patients who are actively using drugs not to share needles with others and to take advantage of the programs that distribute clean needles."[465]

SYRINGE EXCHANGE PROGRAMS

When implemented as part of a comprehensive HIV prevention strategy, SEPs play a unique role in engaging hard-to-reach populations at high risk for HIV infection in effective prevention interventions and treatment. SEPs complement drug abuse treatment by providing drug users with a way to obtain sterile syringes at no cost and an opportunity for those individuals to dispose of used syringes.

SEPs vary in their operation, but in addition to exchanging syringes, effective SEPs provide a variety of other services, including: (1) referrals to addiction treatment programs; (2) HIV testing and counseling, as well as screening for other blood-borne diseases; (3) referrals to other medical and social services; (4) condom distribution and counseling; and (5) nursing services. In addition, many SEPs typically have mobile units that venture out into the community to reach IDUs who may be hard to reach by traditional means.

A large and compelling body of scientific data and literature support the efficacy of SEPs. The Director of the National Institutes of Health, Elias Zerhouni, reported to Congress in October 2004 that "the current scientific literature supports the conclusion that SEPs can be an effective component of a comprehensive community-based HIV prevention effort."[466] Furthermore, Zerhouni reported: "A number of studies conducted in the U.S. have shown that SEPs do not increase drug use among participants or surrounding community members and are associated with reductions in the incidence of HIV, hepatitis B, and hepatitis C in the drug-using population."[467]

In 2004, the World Health Organization (WHO) issued a report that examined every

existing scientific study on the effectiveness of sterile needles and syringe programming in reducing HIV/AIDS among IDUs.[468] The report says: "Measured against any objective standards, the evidence to support the effectiveness of [SEPs] in substantially reducing HIV must be regarded as overwhelming."[469] The report also says that "after almost two decades of extensive research, there is still no persuasive evidence that [SEPs] increase the initiation, duration or frequency of illicit drug use or drug injecting" and further that "there is reasonable evidence that [SEPs] can increase recruitment into drug treatment and possibly also into primary health care."[470]

This recent WHO report echoes a similar one issued in 2000 by U.S. Surgeon General David Satcher. The Surgeon General reviewed a large body of peer-reviewed research on SEPs and stated "there is conclusive scientific evidence that syringe exchange programs, as part of a comprehensive HIV prevention strategy, are an effective public health intervention that reduces the transmission of HIV and does not encourage the use of illegal drugs."[471] After reviewing all of the research to date, the Surgeon General's Report concluded that properly-implemented SEPs lead to: "[1] a decrease in new HIV seroconversions; [2] an increase in the numbers of IDUs referred to and retained in substance abuse treatments; and [3] well documented opportunities for multiple prevention services and referral and entry to medical care."[472] The report furthermore concluded that SEPs do not increase the illegal use of drugs among those individuals participating in the programs and may in fact decrease injection frequency.[473]

Finally, numerous organizations have formally recognized the significance of SEPs and the importance of access to sterile syringes as a means of preventing the transmission of blood-borne diseases such as HIV. In 1999, the American Medical Association, the American Pharmaceutical Association, the Association of State and Territorial Health Officials, the National Association of Boards of Pharmacy, and the National Alliance of State and Territorial AIDS Directors collectively issued a "Dear Colleague" letter urging state leaders in pharmacy, public health, and medicine to coordinate efforts to address access to sterile syringes as a means of prevention.[474] Similarly, the CDC, the National Institute on Drug Abuse, and SAMSHA have issued HIV prevention bulletins regarding IDUs that advise health professionals to counsel IDUs to stop using or injecting drugs, enter into substance abuse treatment, and take measures to prevent or reduce risk through the use of sterile syringes if they continue to inject drugs.[475]

SYRINGE EXCHANGE IN THE DISTRICT

PHARMACY SALES OF SYRINGES

Pharmacies can play a central role in the effort to make clean injection equipment accessible to IDUs via "over the counter" sales or free distribution.476 However, paraphernalia laws sometimes preclude pharmacies from engaging in HIV prevention with IDUs.

The D.C. Code definition of "paraphernalia" includes "[h]ypodermic syringes, needles, and other objects used, intended for use, or designed for use in parenterally injecting a controlled substance into the human body."[477] It currently is unlawful for any person to use, to possess with intent to use, to deliver or sell, or possess with intent to deliver or sell drug paraphernalia if it is to be used, or if one reasonably should know that it will be used, to introduce an illegal substance into the human body.[478] Thus, a pharmacist in the District may not sell or distribute sterile syringes to individuals who the pharmacist reasonably believes will use the syringe for illegal purposes. There is one noteworthy exception to this section of the District's paraphernalia law: the D.C. Code authorizes the Mayor to establish SEPs, "which may provide clean hypodermic needles and syringes to injecting drug users."[479] People participating in SEPs can legally possess and transfer syringes as long as they do so as part of the program.[480]

In order to increase access to sterile injection equipment, the District should consider amending its paraphernalia laws to make clean syringes more accessible through pharmacies. A growing number of states, including Oregon, Wisconsin, Connecticut, Maine, Minnesota, New Hampshire, New York, Rhode Island, New Mexico, and

California, have removed barriers to purchasing syringes at pharmacies.[481]

THE DISTRICT'S SYRINGE EXCHANGE PROGRAM

PreventionWorks! is the District's only authorized SEP. According to their website, the mission of PreventionWorks! is "to curb the spread of HIV and other blood-borne diseases among injecting and other drug users, their sexual partners, and newborn children." The program does this by providing syringe exchange services, as well as drug treatment referrals, HIV testing and counseling, safe sex materials and information, viral hepatitis outreach, support groups, overdose prevention training, food, and clothing.

PreventionWorks!, however, is able to fulfill only a small portion of the District's need for HIV prevention services among injection drug users. In fiscal year 2003, PreventionWorks! reached approximately 3,200 of the District's estimated 9,720 IDUs.[482]

Congress has barred the District from using federal or local public funds to support the distribution of sterile injection equipment. Therefore, only private funds may be used to support this activity. Research has shown that SEPs receiving government funding are more effective at reducing HIV transmission and referring clients to drug treatment programs than SEPs that do not receive government funding.[483] This is because SEPs that receive government funding are far more likely to distribute enough sterile syringes to meet demand and to provide multiple complementary services necessary for a comprehensive HIV prevention network for IDUs.[484]

Significantly, the congressional prohibition does *not* preclude federal or local public funding for complementary services that do not entail the distribution of syringes. Thus, PreventionWorks! is eligible for public funding for services that do not involve the distribution of sterile syringes. Public funding would allow expansion of complementary services that would likely increase the program's effectiveness in preventing the spread of HIV and reducing drug use. Public funding for complementary services would allow PreventionWorks! to allocate a larger percentage of its private funds to additional distribution of sterile syringes, which, as mentioned, is needed in the District. Therefore, HAA should fund supplementary services provided by any SEP.

Once Congress enacted the prohibition on District funding for the distribution of clean syringes, the general perception in the community was that the prohibition put in jeopardy the local and federal funding for any organization operating or associated with an SEP. As noted, this perception is false. Therefore, District officials should ensure that employees of relevant District agencies and CBOs understand that collaboration and co-location with SEPs is permissible. For example, a representative of an organization that provides HIV testing and counseling could provide those services alongside the PreventionWorks! outreach vehicle. HAA should facilitate such collaboration and co-location between SEPs and District agencies and CBOs to strengthen comprehensive HIV prevention services provided to IDUs in district.

SUMMARY OF RECOMMENDATIONS

Data Collection and Dissemination. DOH should gather and disseminate data on the number and characteristics of IDUs and substance abusers in the District in order to target interventions.

Substance Abuse Treatment. The District has insufficient capacity to meet the demand for treatment services. The District should demonstrate a commitment to increasing the availability of substance abuse treatment programs.

Access to Sterile Syringes. Given the overwhelming evidence that SEPs reduce the incidence of HIV without increasing illegal drug use, the District government and advocates should continue efforts to persuade Congress to lift the ban on the use of local funds for syringe exchange programs. In the meantime, HAA should fund complementary services provided by the privately-funded syringe exchange program. In addition, HAA should encourage community-based organizations that provide complementary HIV/AIDS services to

collaborate and co-locate with the syringe exchange program – thereby enhancing HIV prevention among the District's drug users. Furthermore, the District should consider amending its paraphernalia laws to make clean syringes more accessible through pharmacies.

CONCLUSION

HIV prevention with drug users requires a comprehensive strategy with several components. The District currently has no such comprehensive strategy. Although the District provides HIV prevention services for drug users, two of the central components of a comprehensive strategy – substance abuse treatment and access to sterile syringes – are inadequate. HAA should create a comprehensive HIV prevention strategy for all drug users, and District leaders should facilitate implementation of the strategy with all necessary resources. The HIV/AIDS epidemic in this city will continue among drug users and their sex partners until a comprehensive strategy is created and executed.

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PART 2: CHAPTER IX

HIV/AIDS AMONG THE INCARCERATED

CHAPTER INFORMATION:

The HIV/AIDS epidemic disproportionately impacts the incarcerated.[485] The higher AIDS rates among the incarcerated suggest that the population is engaging in risk behaviors prior to or during incarceration, and they have an increased need for HIV education and prevention services. The incarcerated are isolated from the mainstream system of prevention and care while they await trial or serve their sentences, which presents an opportunity for targeted prevention and care services prior to their release back into the community.

This chapter describes the HIV/AIDS services for the incarcerated in detention facilities in the District, as well as reentry services for ex-offenders returning to the community. Recommendations include improved collection and dissemination of data on HIV/AIDS incidence and prevalence among the incarcerated, better coordination and reduction in the number of HIV/AIDS service providers, implementation of rapid testing, expansion of substance abuse treatment, and provision of a 30-day supply of medication to all inmates at detention facilities in the District upon release from custody. In addition, expanded discharge planning services for District inmates in federal facilities are recommended.

HIV/AIDS AMONG THE INCARCERATED

In 2001, 1.9 percent of the prison population in the United States was estimated to be HIV-positive, as compared to less than 0.4 percent of the country's total population.[486] It is very difficult to determine the number of District inmates that are living with HIV/AIDS. The District's 2004 Epidemiological Profile indicates that there were 338 male and 50 female District inmates living with AIDS as of December 31, 2002.[487] The Epi Profile does not indicate whether these inmates are at local detention facilities or in the federal system. More importantly, HAA does not have meaningful current or past data or a mechanism in place to collect data about the prevalence of HIV and AIDS among the inmates at detention facilities in the District.

In early 2005, medical staff at the D.C. Jail reported the recent number of inmates at the detention facilities in the District who are taking antiretroviral medication ranges from about 200 to 235 (about 7 percent of the population).[488] Data on HIV/AIDS among the incarcerated should be collected, analyzed, and disseminated regularly. HAA should regularly conduct a facility-wide anonymous HIV prevalence study to ascertain the severity of the problem in the District's incarcerated population. Such data are important for projecting the need for medical services and discharge planning.

Quick Facts:

- D.C. inmates in D.C. facilities, including halfway houses (average during first half FY2005): **3,490**
- Average length of stay in D.C. facilities: **231 days**
- D.C. inmates in federal facilities (Dec. 2001): **6,930**
- D.C. inmates living with AIDS as of December 31, 2002: **388 total (338 men and 50 women)**

Based on statistics from the D.C. Department of Corrections, *available at* http://doc.dc.gov/doc/frames.asp?doc=/doc/lib/doc/populationstats/DC_Department_of_Corrections_Facts_and_Figures_June_05.pdf (last visited July 24, 2005); Paige M. Harrison & Jennifer Karberg, *Prison and Jail Inmates at Midyear 2002*, BUREAU OF JUSTICE STATISTICS BULLETIN 3 (Apr. 2003), available at http://www.ojp.usdoj.gov/bjs/pub/pdf/pjim02.pdf (last visited July 24, 2005); District of Columbia Department of Health, *The HIV/AIDS Epidemiologic Profile for the District ofColumbia* 36 (Dec. 2003).

DETENTION FACILITIES IN THE DISTRICT

THE DOC AND THE REVITALIZATION ACT

Historically, the DOC functioned as both a local and state correctional system.[489] The Central Detention Facility (D.C. Jail) and the adjacent Correctional Treatment Facility (CTF), which are further described below, detained primarily pretrial and presentence inmates and probation and parole violators.[490] The majority of convicted felons were housed at the Lorton prison complex in Virginia.[491] In 1995, the Lorton facilities housed more than 7,800 prisoners.[492]

In the late 1990s, the DOC was reorganized pursuant to the National Capital Revitalization and Self-Government Improvement Act of 1997 (Revitalization Act).[493] Pursuant to the Revitalization Act, the District closed the Lorton facilities and transferred custody of nearly 8,000 felons convicted in the District to the Federal Bureau of Prisons (BOP) by the end of 2001.[494] As of April 1, 2002, District inmates were scattered among 75 different prisons across the country.[495]

THE D.C. JAIL

At present, the DOC's responsibilities are limited primarily to operating the D.C. Jail. The D.C. Jail houses inmates who are awaiting trial, have been convicted of a misdemeanor offense, or are awaiting transfer to the BOP after conviction of a felony.[496] In 2005, the average daily census levels at the D.C. Jail ranged from 2,148 to 2,339.[497] Medical services are provided by a private contractor selected through a competitive bidding process.

THE CORRECTIONAL TREATMENT FACILITY

In May 1992, the DOC opened the CTF adjacent to the D.C Jail. In March 1997, the DOC entered into a 20-year contract with the Corrections Corporation of America for the operation and management of CTF.[498] Originally designed to serve specialized confinement and health care needs, at present CTF reportedly functions as an "overflow" facility for the D.C. Jail.[499] According to D.C. Jail and CTF staff, there is no difference in the makeup of the two inmate populations, and inmates are shifted back and forth between the two facilities as space requirements dictate.[500] The CTF houses a handicapped unit and an inpatient medical unit. In 2005, the CTF's average daily census ranged from 1,081 to 1,218.[501]

THE D.C. INMATE POPULATION

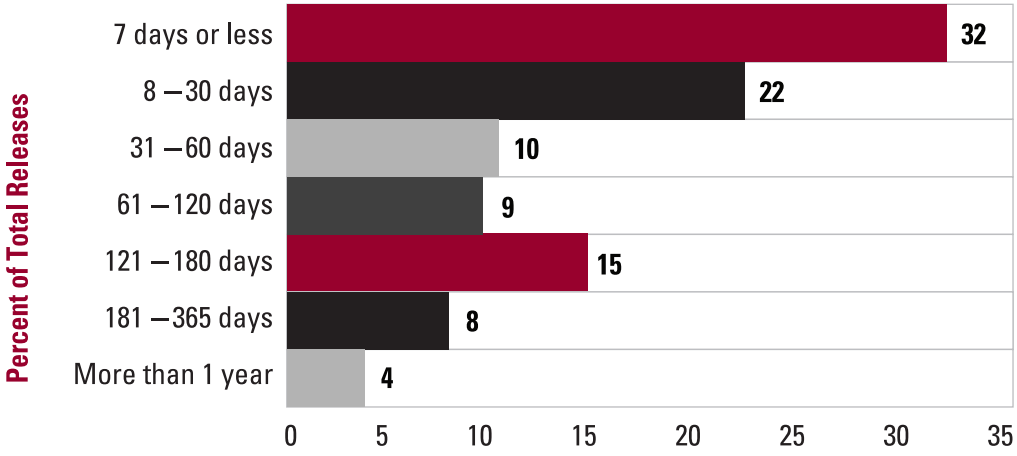
The average length of stay of an inmate in DOC custody is about 231 days, although the majority of inmates stay less than 30 days.[502] Of the District inmates, 88 percent are male and 12 percent are female.[503] The racial breakdown is 92 percent African American, 4 percent Latino, 3 percent White, and 1 percent other.[504]

HEALTH AND HIV/AIDS SERVICES AT THE D.C. JAIL AND THE CORRECTIONAL TREATMENT FACILITY

Currently, the Center for Correctional Health and Policy Studies, Inc. (CCHPS), the DOC's contractor, provides medical and mental health services at the D.C. Jail and CTF and conducts inmate health screening at intake.[505]

To provide HIV/AIDS counseling, testing, prevention, education, and discharge planning to the inmate population, HAA has issued grants to a number of vendors. In addition to a HAA staff member assigned to the D.C. Jail, four HAA-contracted vendors provide HIV/AIDS education, counseling, and discharge planning to incarcerated or formerly incarcerated individuals. Before examining the various services provided, it is necessary to give a brief overview of the vendors involved.

2004 Releases by Length of Stay



District of Columbia Department of Corrections, *D.C. Department of Corrections Facts and Figures* 11 (June 2005)

The following providers conduct a number of HIV prevention activities in the D.C. Jail and the CTF:

- **HAA** assigns a public health advisor to the D.C. Jail, who reportedly spends about 90 percent of his time at the D.C. Jail and is primarily responsible for education, counseling and testing, and coordination of other vendors.[506]
- **Family and Medical Counseling Services, Inc. (FMCS)** has an HIV/AIDS prevention, education, testing, counseling, and discharge planning program called "Project Ujima" at both the D.C. Jail and the CTF.[507] FMCS appears to have the largest presence at the D.C. Jail.
- **Us Helping Us (UHU)** has a grant from HAA to provide discharge planning services to District inmates, both at the D.C. Jail and in the federal prisons.[508] UHU targets MSM and transgenders.[509]
- **Our Place DC** provides discharge planning and HIV prevention services for incarcerated D.C. women through a peer education system.[510] Its work is conducted primarily in federal correctional institutions that house District inmates.[511]
- **Miracle Hands** conducts peer education training and HIV/AIDS education at the D.C. Jail.[512] HAA expected Miracle Hands to address the needs of juveniles and women,[513] but it is unclear whether the organization's services are aimed at those groups. Miracle Hands also provides supportive housing and a day program to HIV-positive ex-offenders, and discharge planning at a halfway house.[514]

Discerning the identities and precise roles of organizations involved in providing HIV/AIDS services at the D.C. Jail and the CTF proved very difficult. Even high-level officials at the DOC were unaware of the number or names of all the organizations that were involved in providing such services to inmates, let alone how various organizations receive referrals or interact with one another.

Of the four HAA grantees, FMCS and Miracle Hands currently have access to inmates at the D.C. Jail.[515] FMCS is the only vendor providing services to inmates in the custody of the CTF, and no other vendors have provided services there in the past. At least one vendor has reported repeatedly seeking access to the D.C. Jail without success, and another has found it difficult to obtain access to inmates at the CTF.

The confusion about who is supposed to have access to inmates under HAA grants and the lack of oversight of their activities may result in duplicative services or in some subgroups not receiving adequate attention

because of a lack of clear delineation of responsibility. The number of vendors appears excessive, particularly given the difficulty in ascertaining which vendors were authorized to have access to the population inside the D.C. Jail and the CTF. Unless DOC knows more about the vendors and their purpose, access issues will continue.

HAA and the DOC should consider establishing or permitting one vendor to provide or coordinate both medical services and all HIV/AIDS services throughout the D.C. correctional system. By having a single vendor, efforts would not be duplicated and the whole population would be better served. At a minimum, the DOC and HAA should reduce the number of providers as well as increase interagency communication.

Other jurisdictions have successfully streamlined HIV/AIDS services in their jails under one vendor or the health department. For example, at the San Francisco County Jail, all medical services, including HIV/AIDS services, are provided to inmates by the Department of Health with collaboration from physicians from the University of California – San Francisco.[516] At the San Diego County Jail, the Sheriff's department works in partnership with university physicians to provide medical services, with nurses in the medical unit conducting HIV counseling and testing and a single CBO providing HIV/AIDS patient management and discharge planning services.[517]

FMCS was the sole provider under the HAA contract until 2002. In 2002, HAA increased the number of vendors, reportedly to improve outreach to special populations within the D.C. Jail, such as transgenders, MSM, and women. Particularly in the case of transgenders and MSM, however, this rationale is dubious because many inmates are hesitant to identify as transgender or MSM for fear of violence or other repercussions in the criminal justice setting. Having multiple providers for different populations presents a practical problem of revealing private information about individuals based on assignment to provider.[518] A single vendor providing services for a variety of diseases and populations may reduce confidentiality concerns and costs.[519]

HIV PREVENTION SERVICES

HIV TESTING AND COUNSELING

CCHPS conducts a thorough physical examination of all District inmates, including a chest X-ray and some routine STD testing for each inmate at intake. Approximately 60 to 80 new inmates arrive at the D.C. Jail each night.[520] According to the D.C. Jail's treatment protocol, "[a]ll DOC inmates [are] evaluated for history, signs, and symptoms of HIV infection during intake and periodic sick call evaluations."[521] However, HIV testing at the D.C. Jail is conducted on a voluntary basis.

D.C. Jail inmates may initiate HIV testing in several ways. First, inmates may request an HIV test during the health assessment component of their initial intake at the D.C. Jail.[522] During the intake process, CCHPS staff informs all inmates of the available testing resources verbally and through a specialized pamphlet.[523] Second, inmates may request an HIV test at any time by completing a sick call form.[524] Completed sick call forms are collected from the housing units on a daily basis and can be accessed only by authorized health care personnel.[525] Third, inmates may request an HIV test from one of the HIV counselors working in the D.C. Jail.[526]

Inmates who request an HIV test are assigned within 48 hours to an HIV counselor provided by HAA or FMCS.[527] Although there is no formal protocol for dividing requests between counselors, staff at CCHPS make assignments based on caseload demands.[528] Once an inmate is assigned to an HIV counselor, the inmate receives both pre-test and post-test counseling services.[529]

If an inmate's test is negative, the post-test counseling will involve discussing that person's risk factors, reiterating the principles of HIV prevention, and recommending testing every six months.[530] If an inmate's HIV test is positive, a range of post-test counseling services is available. CCHPS mental health professionals are available to HIV-positive inmates, as are counselors and HIV-positive peer support groups.[531] Reportedly, if an inmate is released from the D.C. Jail before his or her test results are received, efforts are made to locate and contact the inmate.[532]

At present, FMCS estimates that it performs between 100 and 200 HIV tests per month at the D.C. Jail, but official data on the total number of HIV tests conducted at the D.C. Jail was unavailable.[533] Currently, rapid testing is not being used at the D.C. Jail or the CTF. The D.C. Jail medical staff and HAA grantees should continue to offer testing to the inmate population, but should develop a plan to implement rapid testing. With the rapid turnover at the D.C. Jail and the CTF, it is particularly important for inmates to receive their test results as quickly as possible.

There has been discussion of mandating HIV testing of inmates at detention facilities in the District. In interviews with DC Appleseed Project Team members, numerous correctional medicine experts throughout the country voiced strong opposition to this approach because of inmate privacy and safety concerns. In addition, studies show that jails should focus on counseling, education, and voluntary testing as opposed to mandatory testing.[534] In order to increase the percentage of inmates tested, the DOC and HAA should develop a joint strategy for the implementation of routine rapid testing at detention facilities in the District. The cost implications of routine and rapid testing are discussed in Chapter V.

HIV/AIDS EDUCATION

All inmate HIV/AIDS education at the D.C. Jail and the CTF is voluntary. For the most part, health practitioners at the D.C. Jail employ HIV/AIDS peer education, which they have found particularly effective. FMCS periodically conducts an "HIV 101" course consisting of five to eight sessions. Inmates who complete the course receive a certificate and then can participate in educating their peers in subsequent courses. Peer educators also participate in support groups for HIV-positive inmates, which discuss issues such as transmission, opportunistic infections, and the differences between HIV and AIDS. In addition, Miracle Hands conducts six-week peer education training and HIV/AIDS education classes at the D.C. Jail. FMCS counselors and HAA's public health advisor occasionally make visits to cellblocks at the D.C. Jail to discuss HIV prevention strategies.[535]

At the CTF, FMCS provides an orientation to all inmates, which includes information on infectious diseases, including HIV.[536] FMCS provides group education at the CTF, but there currently is no peer education program in the facility.[537]

The basic training for new employees at the D.C. Jail includes a four-hour educational segment on health precautions, including prevention of HIV, TB, and Hepatitis C. Such programs should be continued.

SUBSTANCE ABUSE TREATMENT

As explained in Chapters I and VIII, substance abuse is a common mode of HIV transmission, and substance abuse treatment is a critical prevention mechanism. The availability of treatment is particularly important for the incarcerated, because substance abuse is so common among offenders. The District's Pretrial Services Agency estimated that in 1999, 69 percent of arrestees tested positive for an illegal substance such as cocaine, marijuana, opiates, methamphetamines, or PCP at the time of arrest, with 25 percent of arrestees testing positive for multiple drugs.[538] Of defendants arrested for burglary, 100 percent tested positive for some drug, along with 85 percent of those arrested for larceny or theft and more than 90 percent of those arrested for drug possession.[539] Over the course of 1999, 46 percent of all defendants tested positive for cocaine, opiates, or PCP at the time of arrest.[540] In addition, almost 70 percent of defendants and offenders under the supervision of the Court Services Offender Supervision Agency (CSOSA) (many of whom pass through the custody of the D.C. Jail or the CTF) have a history of substance abuse.[541]

The Relevance of Substance Abuse

The interplay between substance abuse and the criminal justice system is undeniable. It is estimated that 75 to 80 percent of prisoners "may be characterized as alcohol- or drug-involved offenders." In D.C., many ex-offenders participate in substance abuse treatment programs, both residential programs such as those offered at Safe Haven, and day treatment, such as that available at the Whitman Walker Clinic's Max Robinson Center.

Bureau of Justice Statistics, *Substance Abuse and Treatment, State and Federal Prisoners, 1997*, at 1, *available at* http://www.ojp.usdoj.gov/bjs/pub/pdf/satsfp97.pdf (last visited July 24, 2005).

Given the prevalence of substance abuse among arrestees and defendants, providing sufficient and adequate treatment to inmates at the D.C. Jail should be a priority. The D.C. Jail currently provides a very limited amount of substance abuse treatment. The D.C. Jail offers Safety Net, a 28-day treatment preparation program with the capacity for 80 male inmates and 20 female inmates, to prepare participants for future substance abuse treatment.[542] The DOC recently received a Department of Justice grant to provide a six- to 12-month Residential Substance Abuse Treatment (RSAT) program at the D.C. Jail.[543] Forty men and 20 women will participate.[544] It is aimed at misdemeanants and is available on a court-ordered as well as a voluntary basis.[545] CTF provides a substance abuse education program for 30 males and 30 females.[546]

As explained in Chapter VIII, substance abuse treatment is a vital HIV prevention intervention. Further, studies in D.C. have shown that "involvement in drug treatment programs with regular drug testing and immediate sanctions for violations resulted in a 70 percent reduction in recidivism in the 12 months following completion of the programs."[547] For these reasons and because of the high rate of drug use by inmates, the DOC should expand the number of substance abuse treatment slots at its detention facilities. DOC should explore the possibility of securing additional funding from SAMHSA and other sources to cover the cost of expanding the substance abuse treatment programs at the D.C. Jail.

Many neighboring jurisdictions operate jail-based substance abuse treatment programs that can serve as good models for the District. Funding for these programs is mainly local, but some federal funding is available through the Washington-Baltimore High Intensity Drug Trafficking Area (HIDTA) Treatment/Criminal Justice Initiative.[548] HIDTA provides funding for substance abuse treatment services in 12 jurisdictions surrounding the District and Baltimore, including some treatment services in the District, but the District does not use that funding for jail-based treatment programs.[549] Unfortunately, HIDTA currently does not have any funding available to expand existing programs or fund new programs.[550]

The Montgomery County Correctional Facility, the Arlington County Detention Facility, the Fairfax County Adult Detention Center, and the Prince George's County Corrections Center all house jail-based treatment programs.[551] Most of the programs permit both court-ordered and volunteer enrollment. These programs are designed as therapeutic communities that separate the enrolled inmates from the general population in order to provide intensive, continuous substance abuse treatment and counseling services. In addition to providing treatment to inmates while in jail, there is a focus on reentry and aftercare services that connect released inmates to treatment resources in the community and monitor their progress, sometimes for several years.

Substance Abuse Treatment

Jurisdiction	Approximate Jail Population	Number of Beds for Substance Abuse Treatment	Max. Percentage of Population in Treatment
Prince George's County	1,200 inmates[555]	120 beds[556]	10 percent
Montgomery County	650 inmates[557]	64 beds[558]	9.8 percent
Arlington County	600 inmates[559]	36 beds[560]	6 percent
Fairfax County	1,200 inmates[561]	55 beds[562]	4.6 percent
D.C. Jail and CTF	3,490 inmates[563]	60 beds	1.8 percent

The general model for intensive substance abuse treatment programs for the incarcerated was developed for prisons and requires a long-term commitment that ranges from three months to one year or more. This model excludes the more transient jail population, who may only stay in jail for a month or less. To address this issue, both Prince George's County and Arlington County have short-term treatment options that make intensive drug treatment services accessible to pre-trial inmates and inmates serving one- or two-month sentences.[552] Montgomery County's Jail Addiction Services program also develops alternatives to incarceration for qualifying inmates, such as referrals to inpatient treatment programs outside of jail.[553] Unfortunately, the demand for all of these jail-based treatment options is greater than the program capacity, and all four counties have waiting lists.[554]

The D.C. Jail is lagging behind nearby jurisdictions in terms of the capacity of its

substance abuse treatment programs. This is especially worrisome because the District's high substance abuse rate and HIV/AIDS prevalence may accelerate the spread of HIV/AIDS among drug users and the incarcerated. The CDC has called for increased substance abuse treatment in jails and prisons as a means to combat the spread of HIV/AIDS.[564] Given the high number of inmates with substance abuse problems and the link between substance abuse and HIV transmission, the DOC should take immediate steps to increase the capacity of its substance abuse treatment programs.

CONDOM DISTRIBUTION

The District has a progressive condom distribution policy that should be continued. Various experts indicate that the D.C. Jail is one of the few jails that distributes condoms through official channels.[565] Official DOC policy prohibits sexual contact between inmates, but medical staff and HAA-funded providers are permitted to provide condoms at the D.C. Jail on request.[566] The CTF does not permit condom distribution.[567] Research of condom distribution in jails in other jurisdictions shows varying approaches to the issue, with some permitting but most prohibiting such distribution.[568] The condom distribution program at the D.C. Jail should continue and should be expanded to provide condoms to both male and female inmates at discharge. The DOC should obtain condoms from HAA through the HAA website, as described in Chapter V.

HIV/AIDS TREATMENT

Depending on the inmate's knowledge of his or her HIV status, CCHPS has established several distinct treatment protocols modeled on CDC guidelines.[569] First, inmates with an established history of HIV infection are enrolled in the HIV Chronic Care Clinic.[570] According to the CCHPS protocol, these inmates must receive a medical evaluation by a chronic care physician to assess HIV status within 10 days of their initial intake physical.[571] Second, inmates who currently are on antiretroviral medications and who know the names and doses of their medications are placed on the same medications by the intake physician.[572] Third, inmates who report being on antiretroviral medications who do not recall the names and doses are referred to the sick call clinician for verification of diagnosis and treatment.[573] Fourth, inmates diagnosed with HIV during their stay at the D.C. Jail receive a thorough medical evaluation, conducted by the part-time infectious disease doctor, to determine the appropriate treatment regimen.[574] The DC Appleseed Project Team did not evaluate CCHPS' adherence to these protocols, but close monitoring of adherence to medication regimens is critical to preventing the development of drug resistance among inmates. Such monitoring is particularly necessary when inmates are transferred between facilities.

DISCHARGE PLANNING

Discharge planning prepares inmates for release and reintegration into the community. The process is particularly important for inmates with chronic diseases because, with proper discharge planning, they can leave jail with connections to health care providers and receive care as soon as necessary after release. On the other hand, without discharge planning, newly released inmates can find themselves with no health care provider and no information about their medical records and medication needs. Discharge planning for inmates with HIV/AIDS occurs through CCHPS and FMCS.

In general, FMCS coordinates with CCHPS on the discharge preparations for inmates with HIV/AIDS.[575] For inmates with known discharge dates, FMCS has an established discharge protocol. The inmate is seen by an FMCS case manager within 120 days of a planned discharge, if possible. During this meeting, the inmate and case manager begin the process of contacting community providers and locating health care resources.[576] The most significant obstacle to effective discharge planning is the unscheduled release of inmates.[577] These inmates may not have the opportunity to participate in discharge planning.

On the whole, there are discharge protocols in place that would provide D.C. Jail inmates with the information they need for re-entry into the community. However, these protocols are underutilized because of the number of unscheduled releases and an

apparent lack of communication among various vendors and departments at the D.C. Jail. More coordination between the D.C. Jail Institutional Records Department and the health care providers would increase the number of inmates reached by discharge planners. This could be tied into CCHPS's new policy of making sure each released inmate has received his/her medication or has signed a refusal.

PROVISION OF HIV/AIDS MEDICATION AT DISCHARGE

As HIV-positive inmates leave the D.C. Jail and the CTF, a major concern involves continuity of treatment, particularly for those who are on antiretroviral medication. As mentioned in Chapter VI, any disruption of antiretroviral therapy increases the likelihood of the development of viral resistance. In order to prevent an interruption in treatment, it is critical for an inmate to receive an adequate supply of medication at discharge.

As the primary vendor for medical and mental health services, CCHPS is involved in the discharge of inmates with scheduled releases.[578] Because of the significant number of unscheduled releases, oftentimes the medical staff is not informed prior to an inmate's release. CCHPS' policy provides that upon discharge inmates receive a 7-day supply of their prescribed medications.[579] When an inmate is about to be released, the D.C. Jail Institutional Records Department is supposed to notify the pharmacy staff, who delivers the inmate's medications to the inmate in Receiving and Discharge (R&D); however, there have been reports that this often does not occur. The pharmacy's hours are 8 a.m. to 10 p.m., and there are reports of inmates being released at all hours of the night. A new policy has been instituted that inmates cannot leave until they have either received their medications or signed a refusal, but its impact remains uncertain given the apparent lack of communication regarding releases. An internal review of the effectiveness of this policy should be conducted.

The District should be able to use ADAP funds to purchase an additional three weeks worth of antiretrovirals to provide to inmates upon discharge, thereby providing them with a full month's supply while they transition to community-based HIV/AIDS services.

ADAP FUNDING

HRSA specifically addressed the issue of using ADAP funds for services for the incarcerated through Policy Notice 01-01.[580] While both the Ryan White CARE Act and Policy Notice 01-01 make clear that ADAP funds can be used to purchase HIV/AIDS medications, those authorities also specify a significant limitation on the use of those funds: ADAP funds cannot be used to purchase HIV/AIDS medications where the state (which is defined to include the District)[581] by law is already obligated to provide those medications to the incarcerated or where the state voluntarily has adopted a practice of doing so.[582] Known as the "maintenance of effort" provision, the law and policy require that ADAP funds supplement rather than supplant existing state funding sources for HIV/AIDS medications for the incarcerated.[583]

As the District already provides HIV/AIDS medications to the incarcerated, as well as a 7-day supply at discharge, the "maintenance of effort" requirement prohibits the use of ADAP funds for the purchase of those medications. ADAP funds could be used, however, to purchase an additional 21-day supply to provide to inmates at discharge, provided they have been enrolled in an ADAP program through the discharge planning process.[584] Thus, the inmate would have a full four-week supply of medication while transitioning to community-based services. Because the D.C. ADAP eligibility criteria do not specifically exclude inmates, eligibility determinations could likely be made prior to release.[585]

FEDERAL SUPPLY SCHEDULE PURCHASES

While the District cannot use ADAP funding to purchase those HIV/AIDS medications it already supplies to inmates during incarceration and at discharge, the District is eligible to and does purchase medication through the Federal Supply Schedule (FSS).[586] Prices on the FSS typically offer some level of discount, and in some cases those discounts can be significant. Use of the FSS to purchase HIV/AIDS and other

medications provides a significant source of savings and should be continued.

OTHER ALTERNATIVES

In addition to exploring funding possibilities under ADAP, the District should consider other medication financing options. The District should enroll eligible inmates in Medicaid prior to release, so that Medicaid covers the provision of medication at discharge. The District also should consider partnering with pharmaceutical companies to obtain free medications for inmates at release. For example, Secure Pharmacy Plus, a pharmacy vendor at several correctional facilities around the country, offers HIV-positive inmates discharge planning services and a 30-day supply of free medication through the SecureRelease Program.[587] This program is made possible through cooperation with five major pharmaceutical companies.[588]

DISCHARGE PLANNING FOR D.C. INMATES IN FEDERAL FACILITIES

Since District inmates are now in prisons throughout the country, discharge planning services are essential to ensure adequate health care upon their return to the District.

DISCHARGE PLANNING BY OUR PLACE DC

Our Place DC operates a pre-release discharge planning program for D.C. women at two BOP facilities: Danbury Federal Correctional Institution in Connecticut and Alderson Federal Prison Camp in West Virginia. Our Place also conducts HIV/AIDS peer education programs at the same facilities.

DISCHARGE PLANNING BY THE COURT SERVICES OFFENDER SUPERVISION AGENCY

CSOSA, the D.C. parole and probationary oversight agency, has instituted a pre-release program for District inmates in BOP facilities.[589] CSOSA conducts its program on a quarterly basis at Rivers Correctional Institution (Rivers) in North Carolina, an all-male facility that houses about 1,000 of the roughly 7,000 D.C. inmates in BOP facilities nationwide.[590] Presentations by representatives of community providers, including Unity Health Care and HIV Community Coalition, are made for those scheduled to be released during the next quarter, usually about 200 males.[591] The inmates are also given a packet with important facts and contact information related to medical services.

CSOSA should expand the pre-release program. The videoconferencing format that has been implemented to facilitate participation of local organizations in the Rivers pre-release program should be used to reach inmates in other BOP facilities. The use of videoconferencing should help reduce costs by eliminating the need to travel to Rivers.

REENTRY ISSUES FOR EX-OFFENDERS

Several organizations receive funds to offer assistance to inmates reentering the community, including Our Place DC, Us Helping Us, and Miracle Hands. Like discharge planning services, reentry services help ensure continued health care by referring former inmates to local providers.

Housing Issues

One of the biggest obstacles for ex-offenders is obtaining housing. As explained in Chapter VI, the problems of affordable housing in the District are largely beyond the scope of this study, but they have an enormous impact on reentering inmates. For HIV-positive ex-inmates in particular, the general housing shortage is coupled with the difficulty of finding housing that will accept them. There are a few supportive housing programs that serve ex-offenders, such as Safe Haven and Miracle Hands, but these are insufficient. Lack of housing affects released inmates' well-being directly and indirectly.

SERVICES BY LOCAL VENDORS IN THE DISTRICT

Three local vendors assist ex-offenders with reentry into the community. Our Place DC provides case management, housing and job placement assistance, and other services to formerly incarcerated women. Us Helping Us works primarily with MSM and transgender ex-offenders, helping them link to community services through case management. Miracle Hands provides ex-offenders with supportive housing and also provides traditional discharge planning services at a local halfway house.

SERVICES BY CSOSA IN THE DISTRICT

Some inmates are released from the BOP and placed on parole, whereas others are released directly into the community. Paroled inmates from both the DOC and the BOP become part of CSOSA's Transitional Intervention Parole Services.[592] These inmates are assigned a parole officer to assist them with reentry services and may reside in a halfway house during their initial reentry period. Inmates released without parole supervision are responsible for locating their own health care provider. For those who have not received discharge planning services, obtaining health care coverage and services may be more difficult.

SUMMARY OF RECOMMENDATIONS

Data. HAA should improve collection and dissemination of data on the incidence of HIV/AIDS among the incarcerated. In addition, HAA should conduct regular HIV prevalence studies.

HIV/AIDS Service Provider Access. HAA and the DOC should increase communication and improve coordination of HIV/AIDS services. Rather than maintaining the current system of one vendor for medical services and multiple vendors for HIV/AIDS counseling, testing, and education services, the DOC ideally should have a single vendor provide all of these services in the D.C. Jail and the CTF. At a minimum, the number of HIV/AIDS counseling, testing, and education vendors should be reduced to avoid duplication of services and access issues.

Rapid Testing. Given the rapid turnover at the D.C. Jail and CTF and the potentially high HIV infection rates of the incarcerated, rapid testing should be implemented.

Substance Abuse Treatment. The DOC should augment substance abuse treatment programs for inmates. Given the correlation among substance abuse, incarceration, and HIV infection, substance abuse treatment should be a priority at the D.C. Jail and CTF, and such programs should be expanded.

HIV/AIDS Medication. DOC should institute safeguards to ensure that HIV-positive inmates are not released without medication. DOC should use ADAP funding to provide a 30-day supply of medication at discharge. The District should also enroll eligible inmates in Medicaid at discharge and explore partnering with pharmaceutical companies to provide free antiretrovirals at discharge.

Discharge Planning. CSOSA should increase the number of federal facilities in which discharge planning services are offered to District inmates.

CONCLUSION

Although progress has been made in the quality of health care afforded to the District's inmates and ex-offenders, there are some areas in need of improvement. By ensuring the provision of a sufficient supply of prescription drugs at discharge, the availability of substance abuse treatment, and the coordination of services during incarceration, the District could better address HIV/AIDS among its inmates. In addition, more inmates in the federal system should receive discharge planning services.

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PART 2: CHAPTER X

CONCLUSION

The recommendations set forth in this report will require action by many and will take significant time to implement. To facilitate this process, Appendix B sorts the recommendations according to the agency responsible for their implementation. DC Appleseed is committed to collaborating with the government, providers, and others in implementing the recommendations. In order to track implementation efforts, DC Appleseed will issue periodic updates. Implementation should commence immediately. The health of the District's residents depends on it.

APPENDIX A:

LETTER FROM THE DEPUTY MAYOR

GOVERNMENT OF THE DISTRICT OF COLUMBIA
Office of the Deputy Mayor for Children, Youth, Families and Elders

Neil O. Albert
Deputy Mayor

VIA ELECTRONICALLY

July 5, 2005

Walter Smith, Executive Director
DC Appleseed Center
1111Fourteenth Street, N.W.
Suite 510
Washington, D.C. 20005

Dear Walter:

Thank you and the DC Appleseed project team for meeting with us to discuss DC Appleseed's draft report entitled *The District of Columbia's Efforts to Manage HIV/AIDS Prevention and Care: An Overview and Recommendations for Improvement*. The District looks forward to full collaboration as the Department of Health's HIV/AIDS Administration (HAA), other key District agencies, and private service providers move forward to address a number of critical issues identified in the draft report. I would encourage a spirit of true partnership around the release of the final report, and in working towards the implementation of key recommendations.

I will not repeat all the specific comments on the draft that were shared with you and the project team during our meeting last Tuesday. Instead, I would like to take this opportunity to expand upon four of the areas discussed by Ms. Watts in response to findings made by the project team concerning: 1) a single point of entry system for eligibility and benefits determinations; 2) standards and a quality assurance program for health care providers; 3) website information; and 4) prevention dollars.

With respect to the creation of a single point of entry, we agree on the need for consolidating the eligibility and enrollment processes for major District health coverage programs. As such, we have already begun this process by planning for Alliance eligibility and enrollment to convert to the Income Maintenance Administration (IMA) by spring 2006. We also agree on the need to maximize

Medicaid enrollment over locally funded programs. The Alliance/IMA conversion should maximize Medicaid enrollment and ultimately eliminate the potential for duplicate enrollment.

As the District continues to develop community capacity to serve individuals living with HIV/AIDS, quality of care standards and health outcome measures must be the foundation upon which we build an effective quality assurance program. While we continue to work with community-based organizations to arrive at common expectations for quality health care service delivery and improving services when necessary, we look forward to exploring further ways to ensure that all providers are meeting certain thresholds on critical health care measures for people living with HIV/AIDS. Providers capable of meeting quality of care standards should be the rule rather than the exception.

I agree with the majority of the observations made by the project team concerning improvements that should be made to HAA's website, including direct linkages to other District-agency websites and websites sponsored by HAA. HAA's website can and should be better developed to provide both consumers and providers with information on the various services and resources available. We look forward to working with DC Appleseed in implementing a web development project.

Finally, Section IV of the draft report provides an overview of the funding sources for HIV/AIDS services in the District of Columbia and the management of government grants to community-based service providers. Recently, Mayor Williams committed an additional $1,030,000 in local grant funding from HAA for the provision of services for primary medical care, case management, and testing at two prevention program locations.

Again, thank you for opportunity to preview the draft of DC Appleseed's report *The District of Columbia's efforts to Manage HIV/AIDS Prevention and Care: AN Overview and Recommendations for Improvement*. I look forward to working with you on the release of the final report.

Sincerely,

Neil O. Albert

Cc: Gregg Pane, Director
Department of Health

Lydia Watts, Administrator
HIV/AIDS Administration
Department of Health

APPENDIX B:

RECOMMENDATIONS

HAA

- Expand HAA's website
- Fill vacant positions in the Surveillance Division
- Collect and disseminate HIV and AIDS data and make such data available to the public
- Evaluate HAA's role in working with the CPG, particularly in terms of providing timely and accurate data
- Promote HIV/AIDS reporting requirements and work with the Attorney General to enforce HIV/AIDS reporting requirements
- Combine AIDS and HIV databases into a single database system
- Ensure that surveillance data are reinforced at a remote data storage site
- Reform the grants management system by ensuring that grantees are paid in a timely manner and grant renewals are expeditiously processed
- Implement routine HIV/AIDS testing throughout the District
- Expand the availability of rapid testing
- Increase condom distribution
- Provide prevention case managers with adequate specialized training on a regular basis and facilitate better coordination between prevention case managers and Ryan White case managers
- Collaborate with DMH to provide adequate training on HIV/AIDS issues to mental health workers
- Facilitate prevention interventions, including testing and counseling, education, and condom distribution for the mentally ill at mental health provider sites
- Monitor adherence to revised case management protocols and provide case managers with regular substantive training and current information about available resources and services for their clients
- Fund complementary services provided by the privately-funded syringe exchange program and encourage community-based organizations that provide complementary HIV/AIDS services to collaborate and co-locate with the syringe exchange program
- Consider expanding the ADAP formulary

DOH

- Expand access to STD prevention services and publicize the services
- Implement and enforce routine HIV testing at the District TB Clinic
- Gather and disseminate data on the number and characteristics of IDUs and substance abusers in the District
- In collaboration with HAA, collect data regarding comorbidities
- Institute a pay-for-performance system based on quality assurance standards
- Increase interagency collaboration to improve treatment and care for comorbidities
- Develop a centralized application process, to be administered by IMA, for the enrollment and eligibility verification for Medicaid, the Alliance, Ticket to Work, ADAP, and other programs
- Expand Medicaid benefits to include case management
- Maximize Medicaid enrollment and ensure that all subcontractors who provide Medicaid-covered services are Medicaid certified
- Explore the possibility of increasing Medicaid rates for HIV/AIDS services

DCPS

- Work with the Board of Education to develop school-wide standards regarding which grade levels receive HIV prevention education, what the content of such education is, and the quality of the education provided
- In collaboration with CBOs, develop standardized performance measures for HIV education that are used to evaluate all schools and all HIV/AIDS programs operating in public schools
- Establish guidelines and policies to improve the collection of data regarding HIV/AIDS programs and services in the schools
- Improve coordination of offices responsible for health policy and health education and consider creating a school health office

that includes the liaison to the School Nursing Program, HIV/AIDS Education, and other health-related programs

- Improve communications with the public about DCPS' HIV/AIDS program, including updating the DCPS website with relevant information

BOARD OF EDUCATION

- Work with DCPS to develop school-wide standards regarding which grade levels receive HIV prevention education, what the content of such education is, and the quality of the education provided
- Review and amend the outdated D.C. Municipal Regulations relating to HIV/AIDS in the school system and ensure that school staff is trained regarding these regulations
- Establish an "Advisory Council on Student and School Health" that would include participation from DOH, HAA, CNMC, CBOs, the D.C. Council and Mayor's Office, local children's health advocates, school nurses, parents, and national experts

STD DIVISION

- Provide routine rapid testing at the STD Clinic
- Work with HAA to strengthen HIV prevention efforts through STD prevention
- Ensure that all clients at the STD Clinic receive counseling regarding STD and HIV prevention

APRA

- Increase the availability of and access to substance abuse treatment
- Provide routine rapid testing at all APRA sites

DOC

- Conduct regular HIV prevalence studies of the incarcerated population and make data publicly available
- Work with HAA to increase communication and improve coordination of HIV services in the D.C. Jail and CTF
- Expand substance abuse treatment programs in the D.C. Jail and CTF
- Provide condoms to inmates at discharge
- Institute safeguards to ensure that HIV-positive inmates are not released without medication
- Use alternate funding sources, including ADAP, to provide 30 days of medication to HIV-positive inmates at discharge
- Work with HAA to implement rapid testing at the D.C. Jail and CTF

CSOSA

- Increase the number of federal facilities in which discharge planning services are offered to District inmates

DISTRICT OFFICIALS AND ADVOCATES

- Continue efforts to persuade Congress to lift the ban on the use of local funds for syringe exchange programs

APPENDIX C:

RECOMMENDATIONS FOR IMPROVING THE DISTRICT'S WEB-BASED HIV/AIDS RESOURCES

The Internet has become an important venue for making information available to consumers and providers, advocates and academics, and policy makers and public officials. The District's web-based HIV/AIDS resources should be enhanced.

HAA'S WEBSITE

HAA's website should be an important mechanism for educating the public and informing the community about the HIV/AIDS epidemic in the District. Although the website was modified recently in response to Councilmember Catania's request, the website should be significantly expanded. An examination of other websites of similar HIV/AIDS government agencies throughout the country offers many models for improving HAA's website.

Currently, HAA's website provides a basic description of programs the agency runs or funds and relies on links to external websites to provide consumers with information on HIV/AIDS. One of the website's greatest flaws is the complete lack of basic information on HIV/AIDS, how HIV is transmitted, how HIV/AIDS impacts District residents, and what local resources are available for the prevention and treatment of HIV/AIDS. In addition to external links to educational information, HAA's website should include this basic information about HIV/AIDS, such as the information provided on the HIV/AIDS websites for Illinois, New York City, Seattle/King County, and Maryland.[593] This educational information should be available in multiple languages to meet the needs of District residents for whom English is not a first language.

HAA should also use its website as a resource to educate the public about specific HIV-prevention strategies. On their websites, Seattle/King County and Illinois include information specifically targeted to populations that are at a high risk of contracting HIV.[594] Prevention messages include warnings about risk behavior and guidance on specific harm reduction and prevention measures. Typically, these prevention messages encourage testing. There is limited information on HAA's website about prevention measures. Although HAA's website provides a list of testing sites, it fails to include anything specifically designed to encourage and promote testing.

Furthermore, there is no specific information on services available for HIV-positive individuals. Existing provider lists on HAA's website contain limited information. HAA should maintain an organized resource directory of HAA-funded providers that includes a description of each organization, its address and phone number, the services provided, a description of eligibility requirements, and a link to its website, if one exists.[595]

In addition to providing information for the public and consumers, many jurisdictions use their websites to assist HIV/AIDS providers by providing basic information, training calendars, and contacts for the services available to providers. For example, the Seattle/King County website provides technical assistance to CBOs on grant writing, information management, and organizational and program development, with necessary contact information.[596] HAA's only provider-oriented content is a list of grants available through HAA, with contact information, and links to a limited number of federal grant programs. At a minimum, HAA should include a clear description of the various services and training available to regional providers, with up-to-date contact information for each program. Ideally, HAA would develop a comprehensive collection of resources that providers could rely on for educational materials, guidance, news, and technical support.

HAA's website has eight links to external sites on its "Helpful Links" page. All but two links are for national websites. Many websites include a significantly larger selection of links to other useful sites and resources.[597] HAA's website is especially lacking in links to other local agencies' websites that provide District-specific

information and services. Furthermore, the website lacks clear information regarding enrollment in ADAP, Medicaid, or other services provided through the IMA.

HAA also sponsors two other websites: www.hivcounts.net, which provides information on HIV testing reporting requirements to medical personnel; and www.technetdc.com, a capacity-building project for local providers that gives information on local training and resources available. Neither of these websites is mentioned on HAA's website. These sites should be regularly updated and linked to or merged with HAA's main website.

HAA's website should be expanded to include specific information on HIV/AIDS generally and the state of the epidemic locally. The website should be a resource guide that includes local HIV/AIDS surveillance data, HIV prevention information, a listing of local resources, and relevant information for service providers.

NON-GOVERNMENTAL WEB RESOURCE

In addition to websites operated by local health departments, most major U.S. cities have at least one comprehensive, independent web-based resource on HIV/AIDS operated by a non-governmental, HIV-focused organization that is well recognized by the community – often the local HIV grant-making organization (e.g., AIDS Project Los Angeles and AIDS Foundation of Chicago).[598] One very good reason for this is that a comprehensive web-based resource on HIV/AIDS can provide a critical link to needed information and a neutral forum for widely-dispersed stakeholders in the HIV community.

The District does not have this independent source of information on HIV/AIDS. An organization such as the Washington AIDS Partnership – a philanthropic collaborative affiliated with the National AIDS Fund and Washington Grantmakers – could operate an independent HIV/AIDS website. The website could include:

- **Local news:** News related to the system of prevention and care for HIV/AIDS culled from all of our local news sources, including: the *Washington Post*, the *Washington Times*, the *Washington Blade*, the *D.C. Examiner*, the *Common Denominator*, *City Paper*, the *Current* newspapers (*Northwest Current*, etc.), *Roll Call*, the *Hill*, and others.
- **National news:** Relevant HIV/AIDS-related news from around the country.
- **Calendar:** A comprehensive calendar could include, for example, entries for technical assistance trainings, HIV Prevention Community Planning Group meetings, Ryan White Title I Planning Council meetings, Case Management Operating Committee meetings, Mayor's Advisory Committee meetings, fundraising events, and relevant D.C. Council hearings.
- **Funding opportunities:** This section could include public grant announcements and private grant applications and information.
- **HIV/AIDS 101:** The basics on the epidemic and links to additional information (including the AIDS Education Global Information System, AEGis.com, HIV InSite, and The Body).
- **HIV Services in the District:** A carefully indexed directory (by service type, provider name, etc.) with information about each provider, including contact information, and information on services provided. The directory could include all relevant services, including HIV/AIDS prevention and care, hepatitis C, TB, substance abuse, sexually-transmitted diseases, and mental health.
- **Training/technical assistance opportunities:** Information about all training and technical assistance resources, including the American Psychological Association's Behavioral and Social Science Volunteer Program, and the CDC's training centers.
- **Public documents:** Surveillance reports, data, public hearing testimony, minutes from meetings, local and national protocols, and others.

ENDNOTES

593 *See generally* Illinois Department of Public Health, HIV/AIDS, *available at* http://www.idph.state.il.us/aids/default.htm (last visited July 25, 2005); New York City Department of Health and Mental Hygiene, *HIV/AIDS Information*, *available at* http://www.nyc.gov/html/doh/html/ah/ahbasic.shtml (last visited July 25, 2005); Public Health – Seattle & King County, *HIV/AIDS Program Questions and Answers About HIV and AIDS*, *available at* http://www.metrokc.gov/health/apu/basic/index.htm (last visited July 25, 2005); Maryland Department of Health and Mental Hygiene, *HIV Infection and AIDS*, *available at* http://www.dhmh.state.md.us/AIDS/trnsmit.htm (last visited July 25, 2005).

594 *See generally* Public Health – Seattle & King County, *HIV/AIDS Program Information for Specific Populations*, *available at* http://www.metrokc.gov/health/apu/groups/index.htm (last visited July 25, 2005); Illinois Department of Public Health, *HIV/AIDS: AIDS and Those It Affects*, *available at* http://www.idph.state.il.us/aids/people_affected.htm (last visited July 25, 2005).

595 *See generally* Massachusetts Department of Public Health, *HIV/AIDS, Hepatitis, STD and Substance Abuse Services & Resources* (July 2005), *available at* http://www.mass.gov/dph/aids/services/hivresourceguide.pdf (last visited July 25, 2005); AIDS Office, San Francisco Department of Health, *2003 HIV Prevention and Social Services in San Francisco*, *available at* http://www.sfdph.org/Services/HIVPRevSvcs/2003HIVPrevySocialSvcs4SF.pdf (last visited July 25, 2005); Public Health – Seattle & King County; *HIV/AIDS Program Who Does What in Seattle & King County: Seattle/King County HIV/AIDS Resources*, *available at* http://www.metrokc.gov/health/apu/resources/list.htm (last visited July 25, 2005).

596 *See generally* Public Health – Seattle & King County, *HIV/AIDS Program Technical Assistance for Community Based Organizations (CBO), available at* http://www.metrokc.gov/health/apu/menucbo.htm (last visited July 25, 2005).

597 *See generally* Public Health – Seattle & King County, *HIV/AIDS Program Links to HIV-related Websites*, *available at* http://www.metrokc.gov/health/apu/links/index.htm (last visited July 25, 2005); Maryland Department of Health and Mental Hygiene, *Locating HIV/AIDS News and Information*, *available at* http://www.dhmh.state.md.us/AIDS/infohiv.htm (last visited July 25, 2005).

598 *See generally* AIDS Project Los Angeles, *available at* http://www.apla.org/ (last visited July 25, 2005); AIDS Foundation of Chicago, *available at* http://www.aidschicago.org/home/index.php (last visited July 25, 2005).

APPENDIX D:

THE DISTRICT'S HEALTH CARE COVERAGE PROGRAMS

This appendix summarizes the eligibility requirements and benefits provided by the District's Medicaid program, the Alliance, and Ryan White.

MEDICAID

ELIGIBILITY

The District's Medicaid program applies the five criteria required by federal law to determine whether an individual is eligible for coverage. These criteria are: residency, immigration status, categorical status, income, and resources. Individuals must be residents of the District to be eligible for the District's Medicaid program and must be U.S. citizens or legal immigrants to the country. Legal immigrants are eligible for Medicaid coverage of emergency care, but may not be eligible for the full range of Medicaid services if they entered the United States after 1996.

The District has chosen to alter its categorical, income, and resource requirements, with federal government approval, to allow more residents to be eligible for Medicaid. These requirements are discussed below.

CATEGORICAL ELIGIBILITY REQUIREMENTS

The federal government provides matching funds to states to cover five categories of low-income people: children; pregnant women; adults in families with dependent children; the elderly; and the disabled. These categories reflect Medicaid's historical connection to federal income support programs, such as the Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI) programs. Although many Medicaid beneficiaries do not receive any federal income support, the Medicaid laws continue to use these categories to define eligibility. Unfortunately, these categories tend to exclude many low-income individuals who are young, childless, and not disabled.

Medicaid's categorical eligibility criteria often place low-income people with HIV/AIDS in a "Catch-22."[599] Appropriate therapies may prevent HIV-positive individuals from becoming disabled, yet states are not allowed to provide Medicaid coverage until these individuals become disabled. Childless men are most likely to be affected by this eligibility limitation because they typically qualify for Medicaid only when they become disabled and then can be subject to the lowest maximum income requirement. Women tend to fare slightly better under these criteria because they are more likely to have children in their households, providing access to Medicaid at higher income levels, as discussed below.

It is possible, however, for low-income, HIV-positive individuals to qualify for Medicaid, even if they do not fit into an eligibility category. For example, one may be declared "presumptively disabled." Persons with HIV are considered to be "presumptively disabled if they can document one or more of a

D.C. Medicaid

The following groups are eligible for Medicaid under the District's plan:

- Children up to age 19 and their parents and pregnant women with family incomes at or below 200 percent of FPL;[i]
- Individuals eligible for SSI with incomes at 74 percent of FPL;[i]
- Aged, blind, and disabled persons with incomes at 100 percent of FPL;[i]
- Medically needy individuals with incomes at 53 percent of FPL or couples at 41 percent of FPL;[ii]
- Childless adults aged 50-64 with incomes up to 50 percent of FPL;[iii]
- Uninsured HIV-positive adults who work at least 40 hours per month, with incomes up to 300 percent of FPL;[iv] and
- HIV-positive adults with incomes up to 100 percent of FPL.[v]

Beneficiaries also must meet the District's assets tests, which vary by eligibility category.

i. Kaiser Family Foundation, *District of Columbia: Medicaid Eligibility,* http://www.statehealthfacts.org.

ii. Kaiser Family Foundation, *District of Columbia: Medically Needy Eligability as a Percent of Federal Poverty Level,* 2001, http://www.statehealthfacts.org.

iii. CMS, *Fact Sheet: District of Columbia 1115 for Childless Adults,* http://www.cms.hhs.gov/medicaid/1115/dccafact.pdf.

iv. HAA, *Quarterly Progress Report for the Demonstration to Maintain Independence and Employment Grant (#P-11-91421-3) for July 1, 2004 - Sept. 30, 2004.*

v. CMS, *Fact Sheet: District of Columbia HIV 1115 Demonstration,* http://www.cms.hhs.gov/medicaid/1115/dchiv1115.pdf.

specified listing of opportunistic infections, cancers, or conditions; they need not be diagnosed with AIDS."[600] This status allows individuals to receive SSI benefits and be eligible for Medicaid without waiting for a formal declaration that the individual is disabled. The second way is for the state to use waivers or demonstration programs to expand its Medicaid program. The District has used Medicaid demonstration programs to expand its categorical eligibility options to include HIV-positive individuals who work at least 40 hours per month or who have incomes below the federal poverty line.

Are persons with HIV/AIDS "disabled" for purposes of Medicaid eligibility?

- Persons with AIDS: Generally, yes. If AIDS prevents them from engaging in any "substantial gainful activity."
- HIV-Positive Individuals: Maybe, if they can document one or more of a specified listing of opportunistic infections, cancers, or conditions, they may be declared "presumptively disabled" and thus eligible for Medicaid.

INCOME ELIGIBILITY REQUIREMENTS

The District's Medicaid program meets the minimum federal requirements for income eligibility standards. In some cases, the District has raised the income levels to allow more people to qualify for Medicaid. For example, although the federal minimum requirements set higher income standards for children ages five and below than for those age six and above, the District applies the same higher income standard, 200 percent of the federal poverty level (FPL), to all children, regardless of age, to ensure that all children in a family receive Medicaid coverage.[601]

In most states and the District, individuals who meet the categorical requirements but not the income and resource tests can qualify for Medicaid coverage by deducting their health care expenses from their income (a process called "spending down"). Beneficiaries who use this method are known as "medically needy," as distinguished from the "categorically needy" beneficiaries who meet both the category and income requirements. Federal law defines 28 eligibility categories – combinations of categorical eligibility and income and resource qualifications – that states must cover to receive federal matching funds.[602] Individuals who qualify for these categories are not required to spend down to receive Medicaid benefits. Individuals who qualify for any of the 21 additional optional eligibility categories for which states can receive matching funds, including persons covered under the waiver programs discussed below, can spend down to qualify for Medicaid. This option provides access to Medicaid coverage for some people with HIV/AIDS after they have paid some of their own medical expenses.

RESOURCE ELIGIBILITY REQUIREMENTS

The resource eligibility requirements set an upper limit on the value of assets, including cars and savings, that a beneficiary may own and remain eligible for Medicaid. States' resource standards vary and often are tied to the AFDC standards in place in 1996, when AFDC was ended,[603] or the current SSI standards. The resource level and the methodology used to determine an individual's resources also vary by state and category of eligibility.

The District's resource limits for categorically needy persons are $2,600 for individuals and $3,000 for couples.[604]

Federal Poverty Level in 2005:

- $9,570 per year for one person
- $16,090 per year for a three-person family
- $19,350 per year for a four-person family

Department of Health and Human Services, *Annual Update of the HHS Poverty Guidelines*, 70 Fed. Reg. 8,373-8,375 (Feb. 18, 2005) (last visited July 21, 2005).

SSI Payments for Low-Income Aged, Blind, and Disabled Persons in 2005:

- $6,948 per year for one person

Supplemental Security Income (SSI) In the District of Columbia, SSA Publication No. 05-11162 (Jan. 2005), available at http://www.ssa.gov/pubs/11162.html (last visited July 21, 2005).

BENEFITS

The District's Medicaid program covers a full range of health benefits, which are described in the District's State Medicaid Plan. Under federal law, state programs must cover the following 12 categories of services:

1. Physicians' services;
2. Laboratory and X-ray services;
3. Inpatient hospital services;
4. Outpatient hospital services;
5. Early and periodic screening, diagnostic, and treatment services for individuals under age 21, such as appropriate immunizations, vision services, and dental services;
6. Family planning services and supplies;
7. Services provided by federally qualified health centers;
8. Services provided by rural health clinics;
9. Nurse-midwife services;
10. Certified pediatric nurse practitioner or family nurse practitioner services;
11. Nursing facility services for individuals 21 or over; and
12. Home health care services for individuals entitled to nursing facility services.[605]

District Medicaid beneficiaries usually are not liable for co-payments for these services.

In addition to the services mandated by federal law, D.C. Medicaid also covers prescription drugs, substance abuse treatment services, mental health care, and rehabilitation care. The prescription drug benefit, which is particularly important for individuals with HIV/AIDS, offers many critical drugs at very low cost to the patient. Medicaid beneficiaries in the District pay a $100 per prescription co-payment for each prescription drug they purchase. Under federal law, if a state chooses to cover prescription drugs in its Medicaid program, it must cover all drugs approved by the Food and Drug Administration for which the Secretary of HHS has signed a Medicaid rebate agreement. Although states are allowed to limit coverage through the use of formularies and preferred drug lists and by requiring prior authorization for non-preferred drugs, CMS recommends that states ensure that these limitations "do not excessively or unreasonably restrict coverage of effective treatments (including FDA-approved combination therapy) for HIV/AIDS-infected individuals."[606]

ALLIANCE

ELIGIBILITY

The Alliance provides free health care to individuals and families who:

- live in the District of Columbia;
- have no health insurance; and
- have income at or below 200 percent of the FPL. A member's income (before taxes) must be at or below an amount that is determined by the number of people in his or her immediate family. For example, individuals cannot make more than $19,140 a year, while the annual income for a family of four cannot exceed $38,350.

Applicants are first presumptively enrolled for 30 days from the day they sign the enrollment application. Once eligibility is verified, applicants are enrolled in the program for six months.[607] Every six months a member of the Alliance must re-enroll in the program. At least 30 days before the end of each six-month membership period, a member must call the Member Services Department for help completing the recertification paperwork and to set up an appointment for recertification.[608] As with Medicaid, recertification is required to determine whether any changes in the beneficiary's financial, health, or residency status since the time of last enrollment affect the beneficiary's eligibility for the program.

Applicants are not eligible for the Alliance if they do not meet the three prerequisites discussed above. Applicants are also not eligible if they are enrolled in other medical health benefit programs, such as Medicaid, are receiving Social Security income benefits, or are admitted to a long-term care facility (including nursing homes) for more than 30 days.[609]

BENEFITS

PRIMARY CARE PROVIDER

If members meet the eligibility requirements discussed above, they must then choose an approved primary care provider, who will supervise and coordinate a member's health care. The primary care provider should:[610]

- Ensure that care is complete,
- Diagnose and treat common illnesses and diseases,
- Manage preventative and emergency/urgent care, and
- Refer a member to a specialist when needed.

Every 30 days a member may choose a different approved primary care provider. Members who seek care with a non-Alliance provider are responsible for payment for all services.[611]

SERVICES PROVIDED

The Alliance provides each member with the following health care benefits:[612]

- Provider and hospital care when a member is sick or injured;
- Care to prevent health problems before a member is sick or injured (for example, preventative care in the form of health education programs on HIV and STD care and prevention);
- Emergency Services;
- Urgent care services;
- Prescription drugs;
- Rehabilitation services (physical, occupational, speech therapy);
- Dental services;
- Care for special needs (specialty care); and
- Wellness programs (for example, programs to help children stay healthy through regular checkups and preventative care).

The Alliance does not cover mental health, alcohol, or substance abuse treatment services but does cover some psychotropic drugs. Additional psychotropic drugs that are not covered by the Alliance are available through the DMH.[613]

While the Alliance provides for prescription drug coverage, actually getting prescription drugs may be a challenge. Members must go to one of seven Alliance pharmacies to get a prescription filled. These locations have limited hours and are not open on the weekends.[614] The Alliance provides coverage only for prescriptions listed on its formulary, a list of specific medications in several therapeutic categories. The Alliance formulary does not cover protease inhibitors or antiretrovirals, but Alliance members are eligible to receive these drugs through ADAP.[615]

Pharmacy Coverage Problems

An Alliance member living with HIV/AIDS who also has a mental illness would have to go to two different pharmacies to get medication. The member must go to an ADAP pharmacy for HIV medication and an Alliance pharmacy for other medications.

SPECIALTY CARE

If a member receives care from a specialist who is not listed in the Alliance Provider Directory, the Alliance may cover those services only if the member: (1) receives a referral from his or her primary care provider, and (2) meets all of the Alliance general requirements discussed above. The Alliance will not pay for non-emergency services a member receives from a specialist without a referral from his or her primary care provider.

RYAN WHITE

ELIGIBILITY

To be eligible for Ryan White funding, individuals or families must be uninsured or underinsured and living with HIV/AIDS. Additional specific requirements for funding vary from state to state as discussed below.

BENEFITS

Ryan White primary outpatient and related support services include:

- Physician/clinic visits
- Prescription drugs (through ADAP)
- Case management
- Home health and hospice care

- Dental care
- Housing and transportation services
- Substance abuse treatment
- Health education, risk reduction
- Outreach
- Insurance continuation.[616]

Ryan White does not pay for hospitalizations and long-term institutional care.

ENDNOTES

599 *Financing HIV/AIDS Care, supra* note 160, at 7.

600 Kaiser Commission on Medicaid and the Uninsured, MEDICAID RESOURCE BOOK 20 (July 2002), *available at* http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14259 (last visited July 21, 2005).

601 *Id.* at 11.

602 Centers for Medicare & Medicaid Services, *Medicaid Eligibility Groups and Less Restrictive Methods of Determining Countable Income and Resources* (May 5, 2001), *available at* http://www.cms.hhs.gov/medicaid/eligibility/elig0501.pdf (last visited July 21, 2005).

603 The Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105, replaced AFDC with Temporary Assistance to Needy Families (TANF).

604 Medical Assistance Administration and HIV AIDS Administration, District of Columbia Department of Health, *Operational Protocol for the 1115 HIV Demonstration within the District of Columbia* 5 (Oct. 5, 2004), *available at* http://www.cms.hhs.gov/medicaid/1115/dchivoprprot.pdf (last visited July 21, 2005).

605 Social Security Act, 42 U.S.C. §§ 1396a(a)(10)(A) and 1396d(a) (2003).

606 Letter from Sally Richardson, Director, Medicaid Bureau, Health Care Financing Administration, Department of Health and Human Services, to State Medicaid Directors (June 19, 1996), *available at* http://www.cms.hhs.gov/hiv/hiv61996.asp (last visited July 21, 2005).

607 D.C. Healthcare Alliance, *Member Handbook* 5 (2002), *available at* http://unityhealthcare.org/PDF's/Alliance/Alliance%20Member%20Handbook.pdf (last visited July 21, 2005) [hereinafter *"Alliance Member Handbook"*].

608 *Id.* at 7.

609 *Id.*

610 *Id.* at 23.

611 *Id.* at 24.

612 *Id.* at 4.

613 D.C. Healthcare Alliance, *Drug Formulary 2004,* at 3, *available at* http://www.chartered-health.com/DCHA/DCHA%20_DRUG_FORMULARY_2004.pdf [hereinafter *"Alliance Drug Formulary 2004"*].

614 *Alliance Member Handbook, supra* note 607, at 18.

615 *Alliance Drug Formulary 2004, supra* note 613.

616 *Financing HIV/AIDS Care, supra* note 160, at 12-13.

ACRONYMS

ACHSP	Advisory Committee for HIV and STD Prevention at the CDC
ADAP	AIDS Drug Assistance Program
AHP	Advancing HIV/AIDS Prevention
AIDS	Acquired Immune Deficiency Syndrome
APRA	Addiction Prevention and Recovery Administration
BOP	Bureau Of Prisons
BSSV	Behavioral and Social Science Volunteer Program
CARE	Comprehensive AIDS Resources Emergency Act
CBO	Community Based Organization
CCHPS	Center for Correctional Health and Policy Studies, Inc.
CDC	Centers for Disease Control and Prevention
CMOC	Case Management Operating Committee
CMS	The Centers for Medicare & Medicaid Services
CNMC	Children's National Medical Center
CPG	Community Planning Group
CSOSA	Court Services Offender Supervision Agency
CTF	Correctional Treatment Facility
CTR	Counseling, Testing, and Referral
DASH	Division of Adolescent School Health
DCPS	District of Columbia Public Schools
DMH	Department of Mental Health
DOC	Department of Corrections
DOH	Department of Health
FMCS	Family and Medical Counseling Services, Inc.
FPL	Federal Poverty Level
FSS	Federal Supply Schedule
GLBT	Gay, Lesbian, Bisexual, and Transgender
HAA	HIV/AIDS Administration
HAART	Highly Active Antiretroviral Therapy
HAB	Federal HIV/AIDS Bureau
HCSNA	Health Care Safety Net Administration
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
HRSA	Health Resources and Services Administration
HUD	Department of Housing and Urban Development
IDU	Injection Drug User
IMA	Income Maintenance Administration
MAA	Medical Assistance Administration
MOU	Memorandum of Understanding
MSM	Men Having Sex with Men
OIG	D.C. Office of Inspector General
PEMS	Program Evaluation and Monitoring System
RSAT	Residential Substance Abuse Treatment
SAMHSA	Substance Abuse and Mental Health Services Administration
SEP	Syringe Exchange Program
SSI	Supplemental Security Income
STD	Sexually Transmitted Disease
UHU	Us Helping Us
YRBSS	Youth Risk Behavior Surveillance System

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