REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

Report on Federal Funding for HIV/AIDS Prevention and Treatment Programs in Virginia

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

HOUSE DOCUMENT NO. 6

COMMONWEALTH OF VIRGINIA
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JOINT COMMISSION ON HEALTH CARE: 2005

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December 30, 2005

TO: The Honorable Mark R. Warner, Governor of Virginia
and
Members of the Virginia General Assembly

On behalf of the Joint Commission on Health Care, I respectfully submit a report on recent trends in federal funding from the Ryan White C.A.R.E. Act and other federal funding to Virginia's HIV/AIDS prevention and treatment programs. Item 11B of Chapter 951 of the 2005 Virginia Acts of Assembly required the Joint Commission on Health Care to provide a report for consideration by the 2006 General Assembly Session.

This report, consisting of an executive summary and final report, is submitted for your consideration. The Joint Commission would like to recognize the assistance provided by a number of associations and state agencies in completing this study.

Respectfully submitted,

Kim Snead

Kim Snead
Executive Director

PREFACE

The first case of Acquired Immunodeficiency Syndrome (AIDS) in Virginia was reported in 1982; just one year after the first AIDS case was identified in the United States. For more than 20 years, Virginia has received funding from the federal government for prevention and treatment services related to AIDS and to human immunodeficiency virus (HIV). Item 11B of Chapter 951 of the 2005 Virginia Acts of Assembly directed the Joint Commission on Health Care (JCHC) to conduct a study on federal funding to Virginia's (HIV)/AIDS prevention and treatment programs.

Individuals with HIV/AIDS are living longer and have higher health care costs (medication costs in particular) than ever before. Virginia primarily receives federal dollars for HIV/AIDS services through three funding sources; Medicaid, the Centers for Disease Control (CDC), and the Health Resources and Services Administration which administers funding provided under the Ryan White Comprehensive AIDS Resources Emergency Act (RWCA). This study found that federal funding to Virginia has been reduced for several programs, at a time that the number of individuals living with HIV/AIDS and their related health care costs are increasing.

In response to the study findings, JCHC will introduce a budget amendment and legislation during the 2006 General Assembly Session. The budget amendment will request an additional $265,110 in GFs for each year of the 2006-2008 biennium to expand the CDC-required HIV resistance-testing program in Virginia. The introduced resolution will encourage the School of Dentistry within Virginia Commonwealth University to consider applying for funding under the RWCA Dental Reimbursement Program and the Community-Based Dental Partnership Program. JCHC also voted to include continued monitoring of federal funding for HIV/AIDS services in its 2006 workplan.

On behalf of the Joint Commission on Health Care and its staff, I would like to thank the numerous individuals, agencies, and associations that assisted in conducting this study including; the Department of Health, the Department of Medical Assistance Services, and Virginia Organizations Responding to AIDS.

Kim Snead
Executive Director

December 2005

FEDERAL FUNDING FOR HIV/AIDS PREVENTION AND TREATMENT PROGRAMS IN VIRGINIA

EXECUTIVE SUMMARY

Authority for Study

Item 11 B of Chapter 951 of the 2005 Virginia Acts of Assembly directed the Joint Commission on Health Care to conduct a study on federal funding to Virginia's HIV/AIDS prevention and treatment programs. Specifically, the Commission was charged with analyzing recent federal funding trends regarding the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and additional sources of federal funding provided to the Commonwealth for the prevention and treatment of HIV/AIDS.

Background on HIV/AIDS

Acquired Immunodeficiency Syndrome (AIDS) was first reported in the U.S. in 1981. The next year, the first case of AIDS in Virginia was reported. AIDS is caused by the Human Immunodeficiency Virus (HIV), which progressively destroys the body's ability to fight infections and certain cancers by effectively killing or damaging cells in the human immune system. Although no cure has been found, treatment is available. Prescription medications play a pivotal role in treating HIV/AIDS. Highly active antiretroviral therapy (HAART) is the common term for the use of three or more FDA approved drugs for treatment and is a key component of disease treatment.

From 1999 to 2003, the number of individuals living in the U.S. with AIDS increased 30 percent. During this same time period, the Centers for Disease Control (CDC) reported a 3 percent decrease in AIDS-related deaths, while the number of AIDS diagnoses increased 4 percent. The CDC estimates that by the end of 2003, 1,039,000 to 1,185,000 individuals were infected with HIV in the United States. Of those individuals, it was estimated that 24 to 27 percent were undiagnosed and unaware of their HIV status. In Virginia, approximately 17,000 people are known to be living with HIV/AIDS. The Virginia Department of Health estimates that another 5,000 individuals in Virginia are unaware of their HIV positive status.

Medicaid Coverage for Individuals Living with HIV/AIDS

Medicaid receives the largest portion of federal spending for providing services to individuals with HIV/AIDS. An individual living with HIV/AIDS may qualify for Medicaid if he meets the qualifications of a particular group (low-income children, parents meeting specific income thresholds, pregnant

women, the elderly, and individuals with disabilities) and his income and resources fall below required limits.

Medicaid state plans must provide certain mandatory services to individuals who qualify as categorically needy individuals. Examples of mandatory services that are important to individuals living with HIV/AIDS include inpatient hospital services, physician services, and certain forms of long-term care. States may also choose to provide optional services. Examples of optional services important to individuals living with HIV/AIDS that are available through Virginia's Medicaid program include prescription drug coverage and rehabilitative services. In addition, Virginia provides home and community-based care to individuals with HIV/AIDS through its AIDS Waiver. In FY 2004, 274 individuals received services through the AIDS Waiver. The cost of services provided outside of the waiver to AIDS Waiver participants totaled $6,117,320, with over 60% of this amount a result of pharmacy expenditures. The cost of waiver services totaled $608,497, with the average cost per recipient totaling $2,221.

Centers for Disease Control (CDC) Funding

Part of CDC's mission includes funding activities related to HIV surveillance, research, prevention, and evaluation through local, state, national and international levels. Programs involving epidemiology and surveillance are critical to producing the data necessary to target the delivery of HIV prevention and treatment services.

The Virginia HIV/AIDS surveillance program receives funding from CDC to collect federally-mandated HIV/AIDS infection data. In FY 2005, VDH received $467,556 in federal funding, which is less than the $478,460 received by VDH in 1997. As funding is decreasing, data collection demands are increasing. The CDC has developed Incidence and Resistance Projects in which data on new cases of HIV infection and data on HIV drug resistant infections in newly diagnosed HIV cases are to be collected. To expand the Resistance Project with state funds, $265,110 GFs are needed.

Preventing HIV infection has proven to be more cost-effective than treating an individual with HIV/AIDS. However, federal funding for prevention efforts in Virginia peaked in 2001 at just over $5.2 million. Since that time, funding has decreased by $152,000 or 3 percent (to just under $5.05 million in 2005). In addition, VDH is anticipating another 3 percent reduction in the coming year. As a result of decreased federal funding, several programs have been altered to ensure that funds are appropriated to provide the greatest impact in addition to preserving community-based services to high-risk populations. State funding in the amount of $285,000 GFs are needed to offset the loss of federal HIV prevention dollars. Of the proposed state funding, $150,000 would

address federal rescissions in 2004-2006. The remaining $135,000 of the $285,000 would restore service funds redirected to rent, salary increases, and other administrative costs at the Virginia Department of Health.

In 2003, CDC initiated a new program, the Advancing HIV Prevention Initiative (AHP). The program is designed to reduce barriers to early diagnosis of HIV infection, access to care, and prevention services for individuals living with HIV. VDH must redirect existing funds to meet the objectives of the AHP initiative. New technology has assisted in the attainment of AHP goals. However, the cost of this new technology prohibits its expansion. For example, oral fluid testing requires no needles and may be conducted directly in the community. Rapid testing allows individuals to receive test results in as little as 20 minutes. VDH has established pilot sites using both testing methods but expansion is difficult due to the cost. To address the demands created by AHP, $164,000 GFs are needed.

Health Resources and Services Administration Funding

The Health Resources and Services Administration (HRSA) administers funding provided under the Ryan White Comprehensive AIDS Resources Emergency Act (RWCA). Funding under RWCA was established to provide a safety net for uninsured, low-income individuals who had no other access to care. As a result, funds may only be used as the payer of last resort. The program is the largest federal program designed to provide services for individuals living with HIV/AIDS. RWCA was enacted in 1990, amended and reauthorized in 1996 and 2000, and is being considered for reauthorization.

The following chart displays RWCA funding streams in Virginia.

Funding Stream	Description	Recipients in Virginia	2005 Award
Title I	Provides emergency assistance to severely affected urban areas	Norfolk EMA North. & parts of NW region (DC EMA)	$4,726,063 $4,164,593
Title II	Funds services to provide medications, health care, etc.	State of Va. VDH administers	$22,679,750
Title III	Funds primary care	6 providers statewide	$2,463,520
Title IV	Enhances client access to care & research for women & children	2 providers statewide	$858,391

RWCA Title II. Title II funds are designed to improve the quality, availability, and organization of health care and support services for individuals and families living with HIV. In Virginia, Title II funds support five regional care consortia and the AIDS Drug Assistance Program (ADAP).

The five regional care consortia supported by Title II funding provide client needs assessments, service gap identification, and needed service provision. Federal funds were originally designed to support a system of short-term access to acute care services. For RWCA's FY 2005 (4/1/05 – 3/31/06), Virginia received $5,543,229 in base funding. This was a 6.5% decrease in base funding from the previous year even though there has been an increasing demand for services. VDH estimates that $500,000 GFs are needed to stabilize access to primary care in Northern Virginia alone.

ADAP is designed to provide medications for the treatment of HIV/AIDS to individuals who have limited or no coverage from private insurance or Medicaid. ADAP-earmarked funds have been the fastest growing component of the RWCA appropriation. However, expenditures in Virginia's program have increased 23.8% from FY 2003 to FY 2004. In FY 2005, Virginia was awarded $16,782,217 for ADAP. In addition, Virginia was determined to be a state with a severe need, and, as such, qualified for $1.6 million in ADAP supplemental funds. This federal funding requires a 4:1 federal/state match. Due to increasing program expenditures and longer client enrollment periods, VDH estimates that $4,300,000 GFs are needed to offset the projected shortfall in ADAP funding.

Implementation of the Medicare Part D prescription drug benefit on January 1, 2006 may affect the Virginia ADAP participants who are Medicare beneficiaries. Ten percent of Virginia ADAP participants receive Medicare and will be required to enroll in Medicare Part D. The cost-sharing requirements of Part D will be a difficult change for some ADAP participants, especially if their income is over 150%FPL.

VDH has investigated several methods to assist Part D beneficiaries, including using ADAP funds to cover out-of-pocket costs for Part D beneficiaries and creating a new State Pharmaceutical Assistance Program (SPAP). Creating a new SPAP would allow state funds to count towards Part D beneficiaries' out-of-pocket costs, without affecting access to catastrophic drug coverage. It is estimated that $500,000 GFs are needed to create and implement the program.

Approximately $21 million of the current Title II award requires a federal/state match of 2:1. If this match is not met, federal funding will be decreased. In the past, Department of Corrections' (DOC) expenditures have been used to meet the match. Recently, DOC revised HIV services and

medication contracts and realized savings resulting in a reduced state match; thus jeopardizing Virginia's access to federal Title II funding.

RWCA Title III. Title III provides direct grants to community-based primary health care clinics and public health providers. Funds are distributed through a competitive grant process, with six providers receiving grants in Virginia totaling $2,611,181 for FY 2004 and $2,463,520 for FY 2005. Title III serves as an important vehicle for targeting HIV-related medical services to underserved communities of color and rural areas. HRSA has begun capping the number of Title III providers in the state. Subsequent funding shifts have caused a reduction in funding for the Roanoke area. The estimated annual cost to maintain HIV-related primary care services in Southwest Virginia is $577,000 GFs.

Options and Public Comments

A number of public comments addressed issues other than the proposed options. Six individuals commented regarding the length of the public comment period. The comments received expressed concern that the eight days given for public comment did not provide an adequate time frame for the issue brief to be circulated and commented on by the general public. One commenter did not address any of the specific options, but expressed the importance of community planning and services.

The following options were proposed and public comments received regarding those options. It should be noted that only comments which specifically addressed support for an option were counted as supporting that option. Staff did not attempt to make a judgment call with regard to support. The options that were approved by JCHC are shown in bold text.

Option I: Take no action.
Thirteen comments in opposition to Option I were received.
Robert Atkins.
Fairfax County Department of Health.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Jan Gordon Oellerich.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Virginia Department of Health.
Virginia Organizations Responding to AIDS.
Whitman-Walker Clinic.

Option II: Introduce a budget amendment (language and funding) to expand the HIV resistance testing program.

a) **$265,110 GFs per year of the 2006-2008 biennium;** or

b) other level of funding.

Option II received twelve supportive comments.

Robert Atkins.
Fairfax County Department of Health.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Edward Strickler, Jr.
Virginia Department of Health.
Virginia Organizations Responding to AIDS.

Option III: Introduce a budget amendment (language and funding) to cover federal rescissions in prevention funding.

a) $285,000 GFs; or

b) other funding level.

Fourteen comments supported Option III. Nine of the supportive comments favored (b) with a higher funding amount.

Robert Atkins.
Fairfax County Department of Health.
Bob Kenney.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Edward Strickler, Jr.
Virginia Department of Health.
Virginia Organizations Responding to AIDS.
Whitman-Walker Clinic.

Option IV: Introduce a budget amendment (language and funding) to cover the federal unfunded mandate, Advancing HIV Prevention Initiative.

a) $164,000 GFs; or

b) other amount of funding.

Twelve comments in support of Option IV were received. Seven of those comments supported (b) with greater funding.
Robert Atkins.
Fairfax County Department of Health.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Edward Strickler, Jr.
Virginia Department of Health.
Virginia Organizations Responding to AIDS.

Option V: Introduce a budget amendment (language and funding) to stabilize access to HIV primary care services statewide ~~in Northern and Southwest Virginia.~~
a) ~~$1,077,000 GFs (NOVA $500,000, SWVA $577,000); or~~
b) different amount of funding.
Eighteen comments were received in support of Option V. Of those comments, twelve supported additional funding.
Robert Atkins.
Debby Dimon.
Fairfax County Department of Health.
David Hoover
Bob Kenney.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Jan Gordon Oellerich.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Southwest/Piedmont HIV Care Consortium.
Edward Strickler, Jr.
Virginia Department of Health.
Virginia Organizations Responding to AIDS.
Whitman-Walker Clinic.

Option VI: Introduce a budget amendment (language and funding) to provide additional funding to offset projected ADAP shortfall.
a) $4,300,000 GFs;
b) $3,800,000 GFs ($4.3 million offset by SPAP of $500,000); or

c) other funding level.
Sixteen comments supporting Option VI were received, with one comment specifically supporting funding level (b).
Robert Atkins.
Debby Dimon.
Fairfax County Department of Health.
David Hoover
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Southwest/Piedmont HIV Care Consortium.
Edward Strickler, Jr.
Virginia Organizations Responding to AIDS.
Whitman-Walker Clinic.

Option VII: Introduce a budget amendment (funding and language) to create a SPAP to serve former ADAP Medicare Part D eligible clients.
a) $500,000 GFs; or
b) other amount of funding.
Option VII received fifteen supportive comments. Of those fifteen, one comment supported (b) in an amount higher than $500,000.
Robert Atkins.
Debby Dimon.
Fairfax County Department of Health.
David Hoover
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Edward Strickler, Jr.
Virginia Department of Health.
Virginia Organizations Responding to AIDS.
Whitman-Walker Clinic.

Option VIII: Introduce a resolution, encouraging the Virginia Commonwealth University School of Dentistry to investigate and if appropriate apply for funding under the RWCA Dental Reimbursement Program and the Community Based Dental Partnership Program.

Fourteen comments were received supporting Option VIII. Several comments suggested directing VCU to apply for funding.
Robert Atkins.
Debby Dimon.
Fairfax County Department of Health.
Bob Kenney.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Jan Gordon Oellerich.
Nicolette Solan Pegler.
John Ruthinoski.
Ronald Scheraga.
Blaine Sheffer.
Edward Strickler, Jr.
Virginia Organizations Responding to AIDS.

Option IX: Continue to monitor activities involving RWCA and federal funding by including the issues on the JCHC workplan for 2006.
Thirteen comments were received in support of Option IX.
Arlington Department of Human Services.
Robert Atkins.
Debby Dimon.
Fairfax County Department of Health.
Northern Virginia AIDS Ministry.
Northern Virginia HIV Consortium.
Northern Virginia HIV Consortium Persons with AIDS Committee.
Jan Gordon Oellerich.
Nicolette Solan Pegler.
John Ruthinoski.
Blaine Sheffer.
Edward Strickler, Jr.
Virginia Organizations Responding to AIDS.

In addition to supporting Option IX, several comments included suggestions on what JCHC should explore for next year. The following was submitted by Susan R. Rowland, Executive Director of Virginia Organizations Responding to AIDS:

> *In the next year, the JCHC should review information on:*
> • *The results of work undertaken within the Northern Virginia region to improve the efficient use of public funds in providing treatment services. A project is currently underway in Northern Virginia, requested by the Northern Virginia AIDS Ministry and funded by the Washington AIDS Foundation. Similar support should be made available to providers in all regions of the state in order to maximize public funding for treatment services.*

• Virginia's Medicaid Plan and the trends in services provided to persons living with HIV/AIDS under the Plan, compared to services available in other states. As Ryan White CARE Act funds are diminished, the state's Medicaid Plan provides another option for sharing the cost of care with federal sources.

• Virginia's HIV/AIDS Health Insurance Premium Assistance Program, operated by the Department of Medical Assistance Services. This program is designed to assist persons who are at risk of loosing private health insurance coverage due to loss of income.

• The impact upon Virginia of changes to the Ryan White CARE Act as a result of the expect reauthorization of the Act by Congress this year. The RWCA is authorized for just 5 years at a time, and the Act's authorization expired on September 30, 2005. Reauthorization is expected shortly, and a number of significant revisions are proposed. The JCHC should be informed of these changes, along with the expected impacts upon Virginia's system of prevention and treatment services.

Furthermore, VDH, DMAS, the teaching hospitals, and other major medical care providers that operate programs targeting treatment to persons living with HIV/AIDS should regularly report to the JCHC on the status of prevention and treatment services. Such regular reporting would allow the Commission's members to react proactively with appropriate policy and budgetary responses, assuring that Virginia stays in front of the HIV-virus, and is not driven to higher rates of infection as already seen in other states.

JCHC Staff for this Report

Catherine W. Harrison
Senior Health Policy Analyst

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I. Authority for the Study/Organization of Report

In 2005, Item 11B of Chapter 951 of the 2005 Virginia Acts of Assembly directed the Joint Commission on Health Care to conduct a study on federal funding to Virginia's HIV/AIDS prevention and treatment programs (Appendix A). Specifically, the Commission was charged with analyzing recent federal funding trends regarding the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Also, additional sources of federal funding provided to the Commonwealth for the prevention and treatment of HIV/AIDS were to be examined.

ORGANIZATION OF THE REPORT

The report discusses the incidence and treatment of HIV/AIDS followed by chapters describing the primary sources of federal funding for HIV/AIDS prevention and treatment - Medicaid, the Centers for Disease Control, and Health Resources and Services Administration. The final chapter includes the policy options that were presented to the Joint Commission on Health Care.

II. Overview of HIV/AIDS in Virginia

In 1981, Acquired Immunodeficiency Syndrome (AIDS) was first reported in the United States. Research concluded that the syndrome was caused by the Human Immunodeficiency Virus (HIV), which progressively destroys the body's ability to fight infections and certain cancers by effectively killing or damaging cells in the human immune system. By 1982, the first case of AIDS in Virginia was reported.

The term AIDS is typically applied to the most advanced stages of HIV infection. As the entity responsible for tracking the spread of AIDS in the United States, the Centers for Disease Control (CDC) formulated criteria for defining AIDS. A healthy adult typically has CD4+ T-cell counts of 1,000 or more per cubic millimeter of blood. An HIV infected individual meeting the CDC's definition of AIDS would have fewer than 200 CD4+ T-cells per cubic millimeter of blood. The CDC's definition also includes 26 clinical conditions that affect individuals with advanced HIV. In many cases, these conditions which would normally not affect a healthy individual may prove to be fatal for an individual with an immune system compromised by HIV. Examples of common opportunistic infections found in individuals with AIDS as provided by the National Institutes of Health include:

- Coughing and shortness of breath;
- Seizures and lack of coordination;
- Difficult or painful swallowing;
- Mental symptoms (including confusion and forgetfulness);
- Severe and persistent diarrhea;
- Fever;
- Loss of vision;
- Nausea, abdominal cramps, and vomiting;
- Weight loss and extreme fatigue;
- Severe headaches; and
- Coma.

As with an adult infected with HIV, illnesses which may not pose a difficulty to an individual with a healthy immune system may prove to be quite difficult for a child with HIV/AIDS. Typical childhood illnesses, such as ear infections and tonsillitis, may reach a level of severity not commonly seen in a healthy child.

In addition to opportunistic infections, individuals with AIDS are particularly susceptible to developing certain forms of cancer. Cancers caused by viruses, such as Kaposi's sarcoma and cervical cancer, or cancers of the immune system known as lymphomas, pose a particular threat for individuals with AIDS. These cancers are often aggressive and very difficult to treat.

During the course of HIV infection, most individuals experience a gradual decline in the number of CD4+ T cells. However, some HIV positive individuals may experience abrupt and dramatic drops in their CD4+ T cell counts. The extent to which a person infected with HIV may experience symptoms varies widely. Some individuals become so debilitated by the disease that they are unable to work or function as they would normally. Other individuals with AIDS may experience periods of intense illness followed by periods of time in which they are able to function in a typical manner.

TREATMENT

When AIDS was first reported in 1981, there were no medicines in existence to treat the underlying immune system deficiency. However, since that time, researchers have developed pharmaceutical therapies to fight HIV infection and its associated conditions. Although a cure has not yet been found, the Food and Drug Administration (FDA) has approved a number of drugs for treating HIV.

Nucleoside reverse transcriptase (RT) inhibitors were the first drugs used to treat HIV infection. This class of drugs, known as nucleoside analogs, works by interrupting the virus' ability to make copies of itself. By doing so, the spread of HIV within the body may be slowed, and in conjunction, the start of opportunistic infections may be delayed. The nucleoside analogs class of drugs includes:

- AZT (Azidothymidine);
- ddC (zalcitabine);
- ddI (dideoxyinosine);
- d4T (stavudine);
- 3TC (lamivudine);
- Abacavir (ziagen);
- Tenofovir (viread); and
- Emtriva (emtricitabine).

Non-nucleoside transcriptase inhibitors (NNRTIs) are also available to treat individuals with HIV. Examples of NNRTIs include:

- Delavridine (Rescriptor);
- Nevirapine (Viramune); and
- Efravirenz (Sustiva).

Protease inhibitors are a second class of drugs the FDA has approved for treating HIV infection. This class operates by interrupting the virus' replication later in its life cycle. Drugs in this class include:

- Ritonavir (Norvir);
- Saquinivir (Invirase);
- Indinavir (Crixivan);
- Amprenivir (Agenerase);
- Nelfinavir (Viracept);
- Lopinavir (Kaletra);
- Atazanavir (Reyataz); and
- Fosamprenavir (Lexiva).

Most recently, the FDA has approved a third class of drugs. Fuzeon (enfuvirtide or T-20) is the first approved drug in the fusion inhibitor class. Fuzeon interferes with HIV-1s ability to enter into cells by blocking the merging of the virus with the cell membranes. Thus, HIV's ability to enter and infect human immune cells is inhibited.

HIV may become resistant to any of the FDA approved drugs. As a result, a treatment combining multiple drugs is used to suppress the virus. The common term for the use of three or more of these drugs when used in combination is highly active antiretroviral therapy or HAART.

EPIDEMIOLOGY

According to the Centers for Disease Control, at the end of 2003, it is estimated that 1,039,000 to 1,185,000 individuals were infected with HIV in the United States. Of these individuals, approximately 24 to 27 percent were undiagnosed and unaware of their HIV status. The Virginia Department of Health (VDH) reports that approximately 17,000 people are known to be living with HIV/AIDS in Virginia. VDH estimates that this number under-represents the number of individuals infected since Virginia's living case count is based only on the cases that are reported.

The Kaiser Family Foundation reports that as of December 2003, 902,223 cases of AIDS had been reported in the United States (15,723 cases in Virginia). On the national

level, 18.4 percent of the cases were female. Virginia reflects the national trend with 18.6 percent of individuals being female. However, new AIDS cases reported in 2003 show an increasing number of females. Nationally, 25.8 percent of new AIDS cases in 2003 were female, while 28.7 percent of new cases were female in Virginia. Despite the fact that AIDS case distribution by sex appears to closely mirror national trends, case distribution by race/ethnicity is more variable. Figure 1 displays the comparison between national and Virginia statistics.

Figure 1
Distribution of Cumulative AIDS Cases by Race/Ethnicity in the United States and Virginia
Reported through 2003

Race/Ethnicity	VA #	VA %	US #	US %
White	6,417	40.8	368,731	42.2
Black	8,546	54.4	354,890	40.6
Hispanic	610	3.9	167,168	15.9
Asian/Pacific Islander	101	0.6	6,847	0.8
American Indian	15	0.1	2,912	0.3
Unknown	34	0.2	1,675	0.2
Total	15,723	100.0	902,223	100.0

Source: Kaiser Family Foundation

In Virginia, the average age of individuals at the time that HIV or AIDS infection was reported has increased over time. The increase in the average age appears to be more closely linked to the decrease in younger age groups reporting cases rather than sharp increases of infection in the older population. From 1989 to 2003, the average age of HIV diagnosis increased from 31.8 years to 35.2 years, while the average age of AIDS diagnosis increased from 36.2 years to 39.6 years. Figure 2 displays the average age of HIV and AIDS reported cases in Virginia over five time periods.

Figure 2
Average Age of HIV and AIDS Reported Cases Over Five Time Periods in Virginia Reported through 2003

	1989-1991	1992-1994	1995-1997	1998-2000	2001-2003
HIV age in years	31.8	32.6	33.4	34.5	35.2
AIDS age in years	36.2	36.5	37.2	38.2	39.6

Source: Virginia Department of Health Epidemiology Profile HIV and AIDS in Virginia

The CDC also collects data on the method of exposure to HIV. Both nationally and in Virginia, men who have sex with men represent the largest proportion of cumulative AIDS cases through 2001, followed by injection drug use and heterosexual contact. The following chart outlines the number of cases in Virginia and nationally by method of exposure.

Figure 3
Cumulative AIDS Cases by Exposure Category, Reported Through December 2001

Method of Exposure	Virginia #	Virginia %	US #	US %
Men Who Have Sex With Men (MSM)	7,025	51%	368,643	46%
Injection Drug Use	2,500	18%	201,188	25%
MSM and Injection Drug Use	769	6%	51,241	6%
Hemophilia/Coagulation Disorder	116	1%	5,282	1%
Heterosexual Contact	1,906	14%	90,067	11%
Blood/Tissue Transfusion	273	2%	8,962	1%
Risk Not Reported or Identified	1,253	9%	80,855	10%
Total Cumulative Adult/Adolescent AIDS Cases	13,842	100%	806,238	100%

Source: Kaiser Family Foundation

Advances in treatment have slowed the progression of HIV infection into full-blown AIDS, and thus decreased the number of deaths from AIDS. According to the CDC, a three percent decrease from 1999 to 2003 occurred in AIDS deaths. However, the number of AIDS diagnoses increased an estimated four percent during that same time period. Due to these trends, the number of individuals living in the United States with AIDS increased 30 percent from the end of 1999 through the end of 2003.

Individuals diagnosed with HIV/AIDS require a broad range of services to meet their medical needs. The federal government has served as the primary funding source for services and activities involving HIV/AIDS. The following chapters discuss the major federal funding sources in Virginia including Medicaid, the Centers for Disease Control, and the Human Resources and Services Administration.

III. Medicaid Funded Services for Individuals with HIV/AIDS

Medicaid plays a major role in funding services for individuals with HIV/AIDS. In 1965, Title XIX of the Social Security Act created the federal-state program Medicaid to provide health insurance to primarily low-income children, parents meeting specific income thresholds, pregnant women, the elderly, and individuals with disabilities. States are not required to participate in Medicaid, but if they establish a Medicaid program within their state, they must operate within certain parameters established by the federal government. In exchange, the federal government provides a monetary match for state expenditures. (In Virginia, this match is 50 percent.)

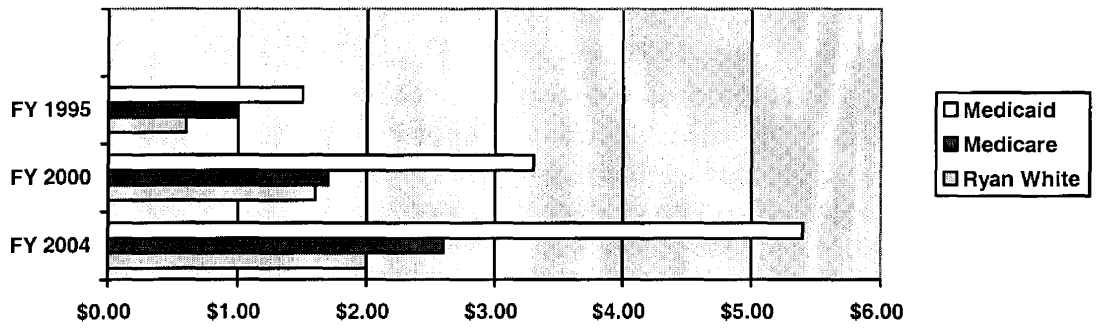
Certain services must be provided by a state that participates in the Medicaid program while there are additional services that states may choose to provide. These mandatory and optional groups apply to Medicaid eligibility as well. Therefore, the number and types of individuals a state covers with its Medicaid program can vary dramatically.

To qualify for Medicaid, an individual must meet the qualifications to belong to a particular group or category. If an applicant does not meet the criteria for a particular group, he will not qualify for Medicaid no matter how low his income or resources may be. The Medicaid statute defines over 50 potential groups for Medicaid eligibility.

Individuals with HIV/AIDS may qualify for Medicaid but they must meet the qualifications of a particular eligibility group in addition to the income and resource requirements. It should be noted that an individual's HIV status does not automatically qualify him as being disabled.

Despite stringent eligibility requirements, Medicaid receives the largest portion of federal spending for providing services to individuals with HIV/AIDS. According to the Kaiser Family Foundation, almost half of federal spending in FY 2004 on HIV/AIDS care was to Medicaid. During the same year, 24 percent was allocated to Medicare, 19 percent to the RWCA and 8 percent to other programs. Figure 4 displays the growth of Medicaid spending in relation to Medicare and RWCA.

Figure 4
Federal Spending for HIV/AIDS Care by Program
(in billions)



Source: Kaiser Family Foundation

MEDICAID STATE PLAN SERVICES

Medicaid State Plans must provide certain mandatory services to individuals who qualify as categorically needy. Several of these services are of particular importance to individuals with HIV/AIDS, including:

- Inpatient and outpatient hospital services;
- Physician and laboratory services;
- Certain forms of long-term care (nursing facility and home health care for those entitled to nursing care).

States may also choose to cover a variety of optional services. All states have opted to provide prescription drug coverage for individuals with HIV/AIDS. In addition, long-term care services are often an integral part of a plan of care for individuals with HIV/AIDS. Beyond the mandatory long-term care services of nursing facility and home health care for those entitled to nursing facility care, states may also provide optional State Plan long-term care services such as personal care and the rehabilitative services option. If states do not wish to provide optional long-term care services to the entire Medicaid population, they may seek a Medicaid waiver. In fiscal years 2003 through 2005, Virginia provided services through the Medicaid State Plan or AIDS waiver to 2,860 individuals with HIV or AIDS who met Medicaid eligibility requirements.

MEDICAID 1915(C) WAIVERS

Typically, Medicaid services must be provided with the same amount, duration, and scope to all Medicaid recipients. However, the federal government allows the states to change some of these requirements by granting them a waiver. All Medicaid waivers that a state implements must be approved by the federal government.

There are several different categories of Medicaid waivers. Most state waivers that provide services, specifically to enable individuals to live in the community, operate under the authority of section 1915(c) of the Social Security Act (SSA). These waivers are frequently referred to as Home and Community Based Services (HCBS) Waivers or 1915(c) waivers.

Under the authority of §1915(c), states may waive Medicaid State Plan requirements such as statewideness, comparability of services, and community income and resource rules. Unlike the Medicaid State Plan, services provided through 1915(c) waivers do not have to be equal in amount, duration, and scope. With this flexibility, states have the option of providing a variety of different services to best meet the needs of the waiver population. In addition, states may target specific populations, such as individuals with HIV/AIDS, or geographic areas. There are currently 16 HCBS waivers throughout the United States that are specifically designed for individuals with HIV/AIDS.

Virginia's Medicaid Waivers

Virginia has five operational Medicaid home and community-based services waivers. They include the:

1. AIDS Waiver;
2. Elderly or Disabled with Consumer Direction (EDCD) Waiver;
3. Mental Retardation (MR) Waiver;
4. Technology Assisted Waiver; and
5. Individual and Family Developmental Disabilities Support (DD) Waiver.

Appendix B contains additional information on each of Virginia's HCBS Waivers.

Waiver programs provide the opportunity for individuals who may otherwise have been institutionalized to live in their homes and community. In recognition of this level of care, individuals enrolled in a waiver must meet the criteria for admission to an

institution, such as a nursing home, hospital, or ICF/MR. Each waiver has an alternate institutional placement. For the AIDS waiver administered by the Department of Medical Assistance Services, the alternate institutional placement is either inpatient hospital or a nursing facility. Both local and hospital screening teams may conduct waiver screenings.

A variety of waiver services, in addition to those provided in the State Plan, are available to individuals enrolled in the AIDS Waiver. These services are designed to provide additional medical support specific to the needs of an individual with HIV/AIDS. Services available through Virginia's AIDS Waiver include:

- Case management;
- Nutritional supplements;
- Private duty nursing;
- Personal care (consumer and agency directed); and
- Respite care (consumer and agency directed).

In FY 2004, 274 individuals received services through the AIDS waiver. This number is less than half of the maximum enrollment level of 653 in 1996. The highest waiver costs of $1,798,958 and per recipient costs of $2,755 were also reached in 1996. In FY 2004, waiver costs decreased to $608,497 with an average cost per recipient of $2,221. Costs for Medicaid services outside of the waiver totaled $6,117,320. Over 60 percent, or approximately $4,000,000, of services provided outside of the waiver was for pharmacy costs.

Total Medicaid expenditures (federal and state funding) for the Commonwealth equaled $4,015,977,621 in FY 2004. (Total expenditures for AIDS waiver recipients were $6,725,817 of the $4.0 billion in Medicaid expenditures.)

IV. Centers for Disease Control Funding

In addition to the federal funding received through Medicaid to serve individuals with HIV/AIDS, Virginia receives funding from the Centers for Disease Control (CDC). As part of its overall mission, the CDC funds a number of activities related to HIV surveillance, research, prevention, and evaluation through local, state, national and international levels. Figure 5 outlines funding allocated from the CDC in FY 2004.

Figure 5
FY 2004 HIV/AIDS Funding Through the CDC for Virginia and the United States

Activity	Virginia	US
HIV Prevention	$5,139,482	$313,559,972
HIV/AIDS Surveillance	$917,221	$59,207,720
STD Prevention	$2,011,249	$101,383,202
Community-Based Organizations and Capacity Building Assistance Providers	$670,815	$86,205,588
Miscellaneous	$868,739	$53,366,471
Total	$9,607,506	$613,722,953

Source: Kaiser Family Foundation

EPIDEMIOLOGY AND SURVEILLANCE

Programs involving epidemiology and surveillance are critical to producing data necessary to target the delivery of HIV prevention and treatment services. In FY 2003, about $40.8 million was provided, out of the CDC's total HIV prevention budget of $699.6 million, to state and local health departments to conduct HIV/AIDS surveillance and epidemiological activities. The data generated by this funding is critical for the Virginia Department of Health to detect emerging trends and effectively allocate resources.

The Virginia HIV/AIDS surveillance program (VSP) is funded by the CDC to collect state and federally mandated HIV/AIDS infection data. It is one of 62 state and territorial programs funded by the CDC. As the state health department, VDH is uniquely situated to collect this important data, due to the expertise, statutory authority, and confidentiality protections already in place within the agency.

VDH receives approximately $1.24 million annually from the federal government to support the VSP activities of Core, Incidence, Resistance, Behavioral, Capacity Building, and Morbidity Monitoring. Each of these programs is necessary to measure the impact and effectiveness of HIV prevention activities. VSP has been recognized nationally as having a model surveillance program. However, Virginia, like many other states, has had its federal funding for this program reduced. In 1997, Virginia received $478,460 in federal funds to conduct surveillance activities. Federal funding levels were reduced to $467,556 by 2005.

The federal funding reduction has affected Virginia's ability to conduct state and federally mandated surveillance activities. The VSP is unable to conduct a death-match evaluation project, a CDC recommended program. In addition, the CDC has requested that states complete two new initiatives, the Incidence Project and Resistance Project. These projects require states to collect information on new cases of HIV infection and HIV drug-resistant infections in newly diagnosed HIV cases. Virginia piloted three local programs in 2004. VDH indicates it will be difficult to meet the CDC's goal of statewide monitoring without additional funding. At the present time, it does not appear that the CDC will be providing additional funding for the Resistance Project. If Virginia wants to fund an expanded resistance testing program, $265,110 GFs would be needed. (This cost estimate assumes testing of 500 specimens.)

In addition, Virginia was one of 14 states that lost long-term federal CDC funding for Pediatric Surveillance in April 2004. CDC rules still require Virginia to measure HIV infection in pregnant women and infants even though funding has been decreased or eliminated. Also, funding for the HIV Behavioral Surveillance project was reduced by 25 percent in 2004. VDH reported that surveillance activities are critical in measuring the impact of HIV/AIDS, in designing effective treatment and prevention programs, and in securing federal prevention and care program dollars.

PREVENTION

HIV/AIDS is a costly disease, both from a financial and social standpoint. Financially, various models propose different costs associated with HIV/AIDS infection. Models for estimating the annual savings for each HIV infection prevented due to prevention efforts range from $6,400 to $49,700. HIV prevention has proven to be much more cost-effective than treating an individual with the disease. HIV treatment costs average about $20,000 a year.

Prevention Activities in Virginia

In 1985, Virginia first implemented prevention services with the introduction of an AIDS hotline. Health education activities in local communities received state and federal funding in 1986 through five regional AIDS service organizations. In addition, Virginia became the first state to offer routine HIV testing in STD clinics in 1986.

In FY 2004, $313,559,972 was allocated for CDC HIV prevention activities and Virginia received $5,139,482. The cooperative agreement between VDH and the CDC provided the following services:

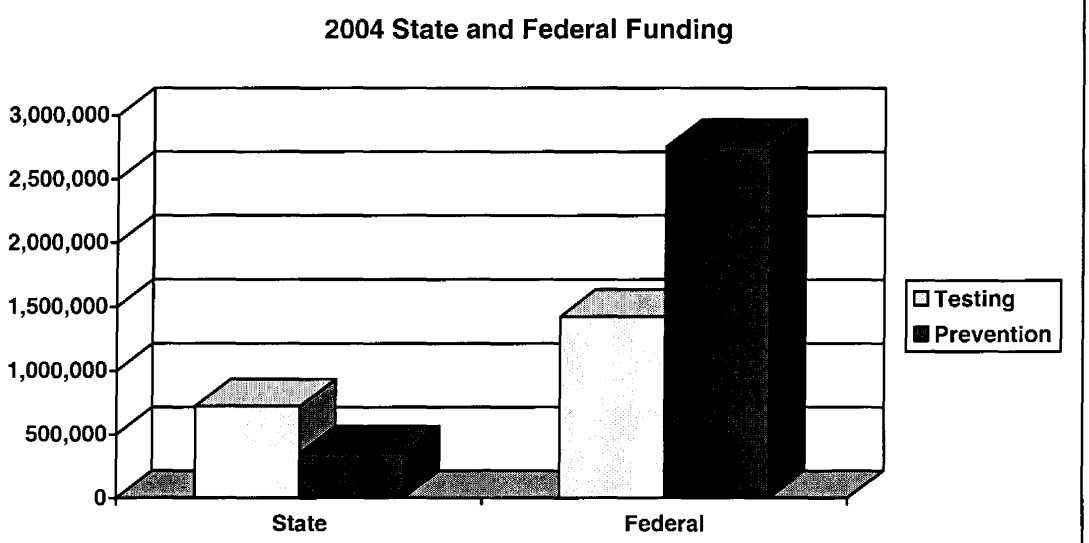
- Counseling and testing;
- Partner counseling and referral services;
- Health education/risk reduction;
- Public information including public information campaigns and hotline services;
- Capacity building;
- Community planning; and
- Evaluation.

Virginia provided funding for mandatory reporting of HIV infection, partner counseling and referral services, and anonymous testing. Figure 6 displays the proportion of funding from the state and federal government.

Federal and state funds are used by the VDH Division of HIV, STD, and Pharmacy Services to fund HIV prevention services in eight grant programs. Six programs are supported solely with federal funds, one program solely with states funds, and one program with a combination of federal and state funds. In 2004, these programs reached 209,189 individuals. In 2005, 22 organizations have been awarded a total of 46 contracts to serve high-risk populations. The eight grant programs that provide funding include:

- AIDS Service Organizations
  - Begun in 1986, this program uses a combination of state and federal funds to support five regional AIDS Services Organizations (ASOs). The ASOs must target at least three increased risk populations.

Figure 6
HIV/AIDS Testing and Prevention Funding in Virginia



Source: Virginia Department of Health

- Minority AIDS Project
  - This program first received funding in 1988 and was reorganized in 2004 to expand services. The Minority AIDS Project funds minority community-based organizations that conduct HIV prevention interventions to racial/ethnic minorities who are at increased risk of infection. The nine localities with the highest HIV/AIDS morbidity among African-American, Latino, and Asian/Pacific Islander communities receive funding.
- AIDS Services and Education Grants
  - This program was created by the General Assembly in 1989 and is funded with state dollars to support street outreach, innovative prevention interventions for difficult populations to reach, case management, volunteer training and support services.
- High Risk Youth and Adult Grants
  - This program, funded in 1997, targets high risk youth, including incarcerated individuals, injection drug users, people who exchange sex for money or drugs, and the homeless.
- African-American and Hispanic Faith Initiative

    - This program was created in 1999 to fund clergy training and congregation education about HIV as well as church mentoring in the development of HIV prevention and support programs through a community mobilization approach.
- Men Who Have Sex With Men HIV Prevention Program
    - Established in 1998, this program targets gay and bisexual men in an attempt to address the disproportionate effect of the HIV/AIDS epidemic on this population.
- OraSure Testing and Intensive Outreach Services
    - Established in 2001, following a successful pilot program, this program provides oral HIV antibody testing in outreach and non-invasive settings through community organizations. The program focuses primarily on men who have sex with men, injecting drug users, and the sexual partners of these populations.
- Primary Prevention for Persons Living with HIV
    - Begun in 2002, this program supports preventing new HIV infections by working with HIV-infected individuals.

Reductions in Federal Funding for Prevention

Federal funding for prevention efforts in Virginia reached its highest level in 2001. Since that time, federal funding provided to VDH has decreased by $152,000 or three percent. (VDH notes, if adjusted for inflation, the impact of the decrease in federal funding since 2001 increases to $165,000 without considering the impact of salary increases or the increased cost of HIV testing.) Additional cuts for HIV prevention are included in the President's 2006 budget. If these reductions are approved by Congress, HIV prevention funding will have been reduced by $10,000,000 since 2004. VDH estimates that they will receive a three percent cut while being required to absorb increased costs in testing, personnel, and rent.

VDH reports that the reduction in federal funding has begun to affect the provision of services within the Commonwealth. The Department has restructured programs in order to ensure that essential programs remain operational. The following programs have been altered to ensure that funds are channeled to where they will have the greatest impact and to where community-based services to high-risk populations will be preserved:

- *The Community Collaboration Projects, which supported models of cooperation in service provision between local health districts and community-based organizations, were eliminated. This eliminated HIV prevention services in two rural areas and a health department education waiting room programs that targeted pregnant women and Latino women.*
- *Minority AIDS Projects, funded through local health districts, were restructured in 2004 so the central office could award funds directly to minority community-based organizations. This action allowed the Division to expand services to two additional high-risk communities while reducing administrative overhead.*
- *Two state-funded anonymous test sites were closed to consolidate services in higher utilization areas.*
- *HIV testing in Family Planning Clinics was discontinued. The low positivity rate among women being tested, coupled with a low return rate for test results contributed to this decision. Funds were reallocated to support new rapid HIV testing technology among high-risk populations in compliance with national priorities.*
- *Three youth advisory committees that provided input into HIV prevention community planning were discontinued.*
- *The AIDS service organization grant program, which funded agencies to cover a specific region, will be eliminated at the end of calendar year 2005. Although the Division indicated a need to move away from the regional approach to more targeted interventions, there are concerns that the action will have a major impact on rural areas where few services are available.*

UNFUNDED MANDATES

In addition to decreased direct federal funding, the burden on states is increasing as the CDC implements unfunded federal mandates. In 2003, the CDC announced the new program "Advancing HIV Prevention Initiative" (AHP), which is designed to reduce barriers to an early diagnosis of HIV infection as well as increasing access to medical care, treatment, and ongoing prevention services for individuals living with HIV. While the CDC decreased funding to states, they also expected states to meet the four strategies outlined in the AHP initiative. Virginia met the requirement that states designate individuals living with HIV as their priority population for prevention services in 2001. However, to meet the other objectives of the AHP initiative, existing program funds will need to be redirected.

The Program Evaluation and Monitoring System (PEMS) was created in 2004 in response to criticism from Congress that national indicators did not exist to show HIV

prevention progress. There is general consensus among state and federal officials that the product of PEMS could prove to be very beneficial and informative. However, the amount of data to be gathered is staggering and no federal funds were allocated to support state efforts.

Within the new five-year HIV Prevention Cooperative agreement with CDC, the federal government has strongly encouraged states to fund Diffusion of Effective Behavioral Interventions (DEBI). DEBIs are a specific set of interventions that have been rigorously evaluated and determined to reduce risk behaviors in high risk populations. Training and curricula associated with DEBIs are available but they are expensive and most training is only offered out-of-state in major metropolitan regions. VDH has several staff who are certified as trainers for one DEBI course, so that it can be offered at no cost to VDH contractors. The CDC has also agreed to offer another DEBI course in Virginia in 2005.

COST OF NEW TECHNOLOGY

Exciting new technologies have emerged that allow VDH to test individuals for HIV. Oral fluid testing for HIV requires no needles or blood, and, therefore, can be conducted outside of the clinic environment and directly in the community. Transportation and fear of needles no longer serve as barriers to testing. The test may also be administered by health educators and outreach workers, therefore, increasing the number of potential test conductors. In addition, rapid testing, which may be either oral or blood, may allow individuals to receive their results in as little as 20 minutes. If an individual receives a positive test result, they will need a confirmatory test.

VDH implemented oral testing through community-based organizations in 2000 and has since had positive findings from this community-based outreach. With oral-based testing programs, the HIV positivity of clients is higher than that of individuals attending STD clinics. In addition, more clients who are tested in a community setting return for their test results. Pilot test sites were developed for rapid testing in 2004.

Unfortunately, despite the initial positive outcomes of these community-based testing techniques, their cost makes expansion prohibitive. A traditional HIV antibody blood test conducted through the Division of Consolidated Laboratory Serves costs $2.50 each for the first 72,500 tests, then $3.68 for each test thereafter. In contrast, an oral fluid test costs $17.36 and a rapid HIV rest costs $10.10. A newly approved rapid oral test will cost around $13.00 each. Despite this reduction from the original oral fluid test, the cost is exponentially higher than the traditional blood test.

FUNDING NEEDS

VDH estimates that $150,000 in GFs are needed to offset the loss of federal HIV prevention dollars resulting from the 2004 and 2005 rescissions and the anticipated rescission in 2006. In addition, $135,000 in state funds was reported to be needed to restore service funds that were redirected to rent, salary increases, and other administrative costs for a total cost of $285,000.

Additional state funds are needed to address the CDC program, Advancing HIV Prevention Initiative, which resulted in unfunded mandates to expand HIV testing and identify additional HIV-infected individuals. The following is a breakdown of budgetary needs as reported by VDH:

$60,000	Support the salary and fringe benefits for a Counseling and Testing Coordinator to work with jails, physicians, hospitals, labor and delivery, etc. to ensure access to HIV testing for high-risk individuals and to provide coordination and quality assurance for the expansion of new test technologies such as rapid testing. In addition, this individual would work with the HIV Surveillance Program to ensure documentation of HIV testing among pregnant women.
$84,000	Funds would be used to expand rapid testing and offset the $3.00 increase in cost per test as OraQuick Advance has replaced OraQuick as the available rapid test option. Funding would cover the cost increase for 15,000 rapid tests and provide funds for $3,000 additional tests.
$20,000	Funds would be used to support the development and distribution of materials targeting pregnant women, obstetricians/gynecologists and labor and delivery units to ensure routine testing of pregnant women and appropriate care and medication for HIV-infected women and their infants to prevent HIV transmission. Subsequently, these funds could be used for other public information efforts to support HIV testing in high-risk populations and communities.
$164,000	**Total**

When taking into account the additional funding needs brought on by federal rescissions and the CDC program Advancing HIV Prevention Initiative, VDH's prevention funding needs are reported to be $449,000.

V. Health Resources and Services Administration Funding

(Under the Ryan White Comprehensive AIDS Resource Emergency Act)

The Health Resources and Services Administration administers additional federal funding provided under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. As the largest federal program specifically designed to provide services for individuals living with HIV/AIDS, CARE Act funds are to be used only as the payer of last resort. The program was established to provide a safety net for uninsured, low-income individuals who have no other access to care.

In 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted by Congress. It was amended and reauthorized in 1996 and 2000 and is once again up for reauthorization. Ryan White, who died four months before the enactment of the legislation bearing his name, inspired the nation with his courageous fight for dignified treatment of individuals infected with HIV/AIDS.

The Ryan White CARE Act (RWCA) states as its purpose:

> *To provide emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HV disease.*

Funding from the RWCA supports primary medical care and support services for low-income, uninsured, and underinsured individuals with HIV/AIDS. According to a 2004 report by the Institute of Medicine of the National Academies, Health Resources and Services Administration (HRSA) estimates that more than half a million individuals each year receive services funded through RWCA. As the nation's largest HIV specific care program, RWCA programs consume 22 percent of federal spending on health care for individuals with HIV/AIDS. The structure of RWCA funding is complex and includes four basic funding streams based upon the title of the Act. Originally, $220,553,000 was appropriated for RWCA in FY 1991. By FY 2005, this amount had risen to $2,073,296,000. Figure 7 displays RWCA funds allocated to Virginia from 2003 until 2005.

Figure 7
RWCA Funding in Virginia

RWCA Funding Stream	Type of Recipient	Recipient in Virginia	2003 Award	2004 Award	2005 Award
Title I	EMAs	Norfolk EMA	$5,168,622	$4,820,201	$4,726,063
		Northern and portion of Northwest regions through DC EMA	$4,222,232	$3,952,335	$4,164,593
Title II	States and Territories	Commonwealth of Virginia (administered by VDH)	$22,152,113	$22,525,348	$22,679,750
Title III	Direct funding to clinics and other providers	6 providers statewide	$2,580,027	$2,611,181	$2,463,520
Title IV	Direct funding to clinics and other providers	2 providers statewide	$819,039	$858,391	$858,391

Source: Virginia Department of Health

Complicating the funding issue is the federal government's requirement of the state to provide matching funds. Approximately $21 million of the current award must be matched with state funds in a 2:1 ratio. In addition, $1.6 million in supplemental funds for ADAP require a 4:1 match. If the state is unable to meet this match, the federal government will reduce its funding accordingly. In the past, HIV-related expenditures by the Department of Corrections (DOC) have been used to meet the requirements of the federal match. However, savings realized by DOC through HIV-related services and medication contract negotiations have resulted in a decrease in available state matching funds. As a result, VDH has attempted to identify all additional state funding sources that may be used as a match.

At the present time, VDH has only been able to identify one minor additional source for the match by channeling $350,000 in current state ADAP funds solely for the purchase of rebate-generating medications. Despite an extensive search, no other funds have been identified by VDH. Moreover, it is uncertain whether ADAP funds will continue to be available in the coming years.

TITLE I

Title I established emergency assistance to Eligible Metropolitan Areas (EMAs). To qualify as an EMA, an area must have reported at least 2,000 AIDS cases during the previous five years and have a population of at least 500,000. When Title I funds were originally awarded in 1991, there were 16 EMAs. In 2004, there were 51 EMAs over an area encompassing 28 states and territories.

EMAs may vary dramatically in size, with HRSA reporting variations including one city or county to more than 26 different political entities. They may even span more than one state. Boundaries of the EMAs are determined by U.S. Census figures. The actual grant is awarded to the Chief Elected Official (CEO) of the city or county providing the health services to the greatest number of individuals living with HIV/AIDS in the EMA. To receive Title I funds, an EMA must establish a HIV Health Services Planning Council.

The HIV Health Services Planning Council should consist of various stakeholders within the community, including individuals with expertise in areas such as health care planning, housing, substance abuse and mental health treatment, or incarcerated populations. Under amendments enacted in 2000 to RWCA, 33 percent of the Planning Council membership should include consumers of RWCA services.

Title I was designed to provide medical and other ancillary and support services. Examples of services that may be provided include:

- Outpatient and ambulatory health services (including mental health and substance abuse treatment);
- Outpatient and ambulatory support services that facilitate, enhance, support or sustain delivery continuity or benefits of health services;
- Early intervention services that may include outreach, counseling and testing, and referral services designed to identify HIV-positive individuals who know their HIV status; and
- Inpatient case management that expedites inpatient discharge and readmission.

Title I funding to EMAs includes formula and supplemental components, in addition to Minority AIDS Initiative, which targets services to minority populations. The estimated number of living cases of AIDS over the most recent 10-year period are used to calculate formula grants. In addition, Title I funding formulas contain hold-harmless provisions that protect grant recipients from decreases in funding from one year to the next. EMAs have additional protections under a grandfather clause which

stipulates that once a metropolitan area has become an EMA, it will still receive funding under Title I, even if its caseload falls below the established threshold for eligibility. New provisions from RWCA reenactment in 2000 provide that formula funds will be based upon AIDS cases and HIV infections that have not yet progressed to AIDS by 2007. As of June 2005, this change had not been implemented. Other supplemental grants are based on demonstration of severe need and other criteria and are awarded competitively.

In FY 1991, $87,831,000 in funding was provided by the federal government. By FY 2005, this amount had increased to $617,720,000. However, the amount of Title I funds appropriated has been decreasing since it reached a high in FY 2003 of $626,649,000. The two EMAs located in Virginia mirror the decrease in federal appropriations. Figure 8 displays the EMAs most recent awards.

Figure 8
EMA Title I Funding Awards in Virginia

EMA	2003 Award	2004 Award	2005 Award
Norfolk EMA	$5,168,622	$4,820,201	$4,726,063
Northern and Portion of Northwest Regions through DC EMA	$4,222,232	$3,952,335	$4,164,593

Source: Virginia Department of Health 2005

TITLE II

Title II provides funding to all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and other eligible U.S. Pacific Territories and Associated Jurisdictions. Programs supported by Title II funding are designed to improve the quality, availability, and organization of health care and support services for individuals and families with HIV. Funding from Title II can be separated into several different programs including:

- Base Title II funding;
- Emerging Communities (EC);
- Minority AIDS Initiative (MAI); and
- AIDS Drug Assistance Program (ADAP).

Federal appropriations for Title II increased from the original FY 1991 appropriation of $87,831,000 to $1,135,859,000 in FY 2005. Unlike Title I funds which have been decreasing since FY 2003, Title II appropriations have increased at approximately three percent a year during this same time. However, the rate of increase in Title II funding received by the Commonwealth does not match that of the overall federal appropriation. In 2003, Virginia was awarded $22,152,113, followed by a 1.7 percent increase in 2004 to $22,525,348. In 2005, the funds received from HRSA increased only 0.7 percent to total $22,679,750. Figure 9 displays the allocation of Title II funds in Virginia.

Figure 9
Distribution of Title II Funds in Virginia for FY 2005

Title II Program	Federal Funding Amount
Base Funding	$5,543,229
ADAP	$16,782,217
Emerging Communities	$241,396
Minority AIDS Initiative	$112,908
Total	$22,679,750

Source: Virginia Department of Health

Title II Base Funding

Title II base funding is distributed to all 50 states, the District of Columbia, and eight territories. Like Title I, funding is based upon a formula involving the estimated living AIDS cases over the most recent ten-year period. Estimated living AIDS cases residing within an EMA are included in the formula but receive less funding per case due to their receipt of Title I funding. By 2007, HIV cases should be included in the funding formula. However, as of June 2005, this had not been accomplished.

Title II guidelines exist for minimum amounts that states may receive. If a state has less than 90 living cases, they receive a minimum Title II base grant of $200,000. For states having over 90 living cases, they receive $500,000 at a minimum. In addition, territories automatically receive a minimum of $50,000. States may be required to provide a match with their own resources if the state contained more than one percent of total AIDS cases reported in the United States during the previous two years.

Title II Funding and Programs in Virginia. In FY 2005, VDH received $5,543,229 for Title II base funding. (The RWCA fiscal year 2005 spans from April 1, 2005 until March 31, 2006.) The FY 2005 allotment was a 6.5 percent reduction in base Title II funding from the previous year. Title II base funds are used to cover health care and support services, program administration, planning and evaluation, and quality management. In order to reduce the effect of funding reductions on these services, VDH made administrative and planning/evaluation budget cuts totaling over $182,000. In 2005, VDH will use less than 4.9 percent of its Title II award to fund administrative, planning and evaluation, and quality management activities. In addition to these reductions, support for direct services had to be reduced by slightly over $200,000.

RWCA Title II funds are used to support five regional care consortia which assess client needs, identify service gaps, and provide needed services. Each consortia is headed by a lead agency which is responsible for administration and the coordination of consortium activities. Current consortia include:

- Central Virginia HIV Care Consortium: Virginia Commonwealth University, Center for Public Policy Survey, and Evaluation Research Laboratory;
- Eastern Regional HIV Care Consortium: Eastern Regional AIDS Resource and Consultation Center;
- Northwest HIV Care Consortium: James Madison University, Institute for Innovation in Health and Human Services;
- Northern Virginia HIV Consortium: Northern Virginia Regional Commission;
- Southwest/Piedmont HIV Care Consortium: Council of Community Services.

When RWCA was first enacted in 1990, the needs of individuals living with HIV/AIDS were different. The progression of the disease before the pre-HAART (highly active antiretroviral therapy) era of drug treatment typically led to disability and death. As a result, the system was designed to handle short-term access to acute care services to terminally ill individuals. Today, the system must provide medically complex, chronic care to HIV infected individuals for long periods of time. Over the last two years, the average duration of services for individuals receiving care through the consortia has increased 36 percent. In grant year 2004, over 3,400 depended on consortia services for access to primary care, an increase in clients served of 28 percent from 2002.

VDH reports that current funding levels are inadequate to fund services for all RWCA-eligible individuals. The Northern Virginia region, in particular, has experienced acute funding issues. There has been a waiting list of four to six weeks for

clients to access primary medical care. In addition, the Whitman Walker Clinic, a key primary care provider, announced that it will be closing its clinic in Northern Virginia. Other regions of the state are also beginning to experience these increased waiting times and increased access problems.

Emerging Communities

Cities reporting between 500 and 1,999 estimated living AIDS cases in the most recent five years are categorized as Emerging Communities (ECs), and as such are eligible for supplemental grants under Title II. Due to the funding formula, the number of ECs may change from year to year. Funding is calculated as follows:

- $10 million or 50% of new Title II base funding, whichever is greater to ECs.
  - The greater of 25% of EC funding or $5 million is allocated for tier one (1,000 to 1,999 cases).
  - The greater of 25% of EC base funding or $5 million is allocated for tier two (500 to 999 cases).

In FY 2005, the Richmond area received $241,396 as an EC.

Minority AIDS Initiative

The Minority AIDS Initiative (MAI) is designed to increase minority participation in AIDS Drug Assistance Programs and other HIV-related services. Funds are distributed by HRSA based on an estimated living AIDS case formula based on disease burden in minority populations. Federal funding for MAI totaled $6,913,000 in FY 2004. Virginia received $145,007 of this funding. Virginia received the decreased amount of $112,908 in FY 2005.

AIDS Drug Assistance Program

Additional federal Title II funds are earmarked for the AIDS Drug Assistance Program (ADAP). ADAP is designed to provide medications for the treatment of HIV and AIDS to individuals who have limited or no coverage from private insurance or Medicaid. States may also use funds to purchase health insurance for eligible clients. When RWCA was reauthorized in 2000, amendments added language allowing ADAP funds to also be used to pay for services that enhance access, adherence, and monitoring of drug treatments.

Funds are earmarked by Congress specifically for ADAP. Historically, ADAP-earmarked funds have been the fastest growing component of RWCA appropriations. From 1996 to 2002, funding increased more than 1,000 percent. States are awarded ADAP-earmarked funds based on a formula using each jurisdiction's estimated living AIDS cases (including EMA and non-EMA regions) over the most recent ten-year period. ADAP funding increased from $748,872,000 in FY 2004 to $787,521,000 in FY 2005. For FY 2005, Virginia received $16,782,217 for ADAP funding.

States may also receive ADAP supplemental funding. Three percent of ADAP-earmarked funds are set aside to provide grants to states with severe need. For a state to receive funding, its program must also meet one of the following conditions:

- Financial eligibility at or below 200% FPL;
- Medical eligibility restrictions;
- Limited formulary composition for the treatment of opportunistic infections.

The amount of supplemental funding provided to a state is determined by using the same living AIDS cases formula that determines state ADAP awards. For every $4 in federal ADAP supplemental funding, the state must provide $1 in funding. Currently, Virginia receives $1.6 million in ADAP supplemental funds. VDH has indicated that state matching funds are unlikely to be available unless additional funds from the state are allocated specifically for this purpose. Figure 10 displays ADAP funding in Virginia over a four-year period.

Figure 10
ADAP Funding

	RW GY 2002	RW GY 2003	RW GY 2004	RW GY 2005
Title II ADAP Earmark	$13.3 million	$13.9 million	$14.5 million	$15.2 million
Title II ADAP Supplemental	$1.8 million	$1.8 million	$1.7 million	$1.6 million
State funds (awarded for the state fiscal year)	$2.6 million	$2.6 million	$2.6 million	$2.6 million
Total	$17.7 million	$18.3 million (+3.4%)	$18.8 million (+2.7%)	$19.4 million (+3.2%)

Ryan White Title II funds are awarded to states on a formula basis. The Title II grant year runs from April 1-March 31 and is designated by the year it begins.
Source: VDH

ADAP Funding and Expenditures in Virginia. Virginia's ADAP provides life-sustaining medications to low-income individuals living with AIDS. Individuals must have an income below 300% of the FPL or 333% of the FPL in Northern Virginia. However, the program faces an ever-increasing number of challenges, including increased program demands and uncertain funding prospects.

Expenditures in the program increased 23.8 percent from FY 2003 to FY 2004. Although enrollments remained stable, discharges from the program slowed, creating longer enrollment periods and program growth. This growth can largely be attributed to the success of current treatments in sustaining life. The success in treatment has also kept many individuals from qualifying as disabled and possibly receiving services through Medicaid. Figure 11 displays three years of Virginia ADAP utilization measures.

Figure 11
ADAP Service Utilization Measures

Service Utilization Measures	FY 2002	FY 2003 (% change FY02-03)	FY 2004 (% change FY03-04)	% change FY02 to FY04
Average # clients receiving prescriptions/month	1,464	1,520 (+3.7%)	1,673 (+9.2%)	+12.5%
Average length of ADAP enrollment in months	22.4	24.8 (+9.7%)	27.4 (+9.5%)	+18.2%
Total clients served/year	2,997	3,102 (+3.4%)	3,322 (+6.6%)	+9.8%
Average # of prescriptions filled/month	4,833	4,996 (+3.3%)	5,701 (+12.4%)	+15.2%
Total # of prescriptions filled/year	58,004	59,959 (+3.3%)	68,421 (+12.4%)	+15.2%
Average cost/client/month	$916	$962 (+4.7%)	$1051 (+8.4%)	+12.8%
Average monthly expenditure	$1,342,764	$1,463,431 (+8.2%)	$1,761,795 (+16.9%)	+23.8%

Source: Virginia Department of Health

In an attempt to maximize ADAP funds, VDH has employed several methods. When it is found that an ADAP client is eligible for Medicaid, VDH bills the Department of Medical Assistance Services. Also, negotiations with pharmaceutical companies by a national ADAP Task Force have resulted in significant rebates and discounts. The combined savings of these two strategies is over $150,000 per quarter. VDH reports that these cost-savings are not enough to cover the demand for services, however, given the small increases in federal funding and stagnant state funding in recent years.

Medicare Part D Will Impact ADAP

The new Medicare Part D prescription drug benefit which will become effective January 1, 2006 will have a significant impact on ADAP. Ten percent of Virginia ADAP participants are Medicare beneficiaries and will be required to enroll in Medicare Part D in order to maintain ADAP eligibility. Under the standard prescription drug benefit offered with Medicare Part D in 2006, beneficiaries will:

- Pay the first $250 in drug costs (deductible);
- Between $250 and $2,250, pay 25 percent of total drug costs;
- Between $2,250 and $5,100, pay 100 percent of total drug costs;
- Once the catastrophic threshold for drug costs of $5,100 is reached, the individual pays the greater of $2 for generics, $5 for brand drugs, or 5 percent coinsurance.

For an individual to access catastrophic coverage, they must spend $3,600 in out-of-pocket costs. This is in addition to monthly Part D premiums. However, individuals with income below 150% of the FPL may qualify for additional assistance in covering their prescription drug costs. These cost-sharing requirements will create a significant change for ADAP clients who have previously received their medications without any out-of-pocket expense. Concerns have been expressed that this significant increase in out-of-pocket expenditures may be a threat to individual as well as public health. As a result, VDH has investigated methods to assist ADAP Medicare beneficiaries with premiums, co-insurance, and co-payments.

HRSA has stipulated that any changes made to a state's ADAP to cover Part D costs must be cost neutral. In addition, ADAP funds contributed towards the cost of prescriptions cannot be counted as part of the individual's out-of-pocket expenses. By not being able to count ADAP funds, the individual will be unable to meet the catastrophic coverage level. Therefore, cost-savings to the ADAP program would be minimal at best.

A new State Pharmaceutical Assistance Program (SPAP) may be a more appropriate way to supplement ADAP clients who are eligible for Medicare Part D. Unlike, ADAP funds, SPAP funds used to assist clients with prescription drug costs may be counted towards the individual's out-of-pocket expense. Therefore, once the out-of-pocket limit is reached, Medicare catastrophic drug coverage becomes available. The federal government has not provided complete parameters for a program of this nature. However, legislative action at the state level would be necessary to create an SPAP.

TITLE III

Title III of RWCA provides direct grants to over 425 community-based primary health clinics and public health providers across the United States. It serves as an important vehicle for targeting HIV-related medical services to underserved communities of color and rural areas. Title III services may include HIV counseling and testing, medical evaluation and referral, and outpatient clinical care. Funds are distributed to service providers through a competitive grant process administered by HRSA. According to the Kaiser Family Foundation, Congress appropriated $186,713,790 in FY 2004. VDH reports that six providers received grants in Virginia totaling $2,611,181 for FY 2004 and $2,463,520 for FY 2005. Grants from these funds typically fall into one of three categories including:

- Early Intervention;
- Capacity Building; and
- Planning.

Early intervention services program funds provide primary health care for individuals living with HIV disease. Community Health Centers, Comprehensive Hemophilia Diagnostic and Treatment Centers, and federally qualified health centers are a few examples of potential grantees. A wide variety of services may be provided through these grants including:

- Risk reduction counseling and prevention, antibody testing, medical evaluation, and clinical care;
- Antiretroviral therapies, ongoing medical, oral health, nutritional psychosocial, and other care services for HIV infected clients;
- Case management; and
- Treatment of other health problems that commonly occur with HIV infection, including tuberculosis and substance abuse.

To receive Title III capacity-building grant funds, an applicant must be a public or private nonprofit entity that is or intends to become a comprehensive HIV primary care provider. Current RWCA service provider grantees may apply if they have been a grantee for no more than three years and serve communities of color, rural or underserved areas. The capacity-building grant program is designed to provide funds to strengthen grantees' organizational infrastructure and enhance their capacity to develop, enhance, or expand high quality HIV primary health care services in rural or

urban unserved areas and communities of color for a fixed period of time, typically one to three years. Service delivery is not funded through this grant program.

Title III planning grants also target rural or urban underserved areas and communities of color. Funds are awarded for one year and are intended to assist eligible entities in their efforts to plan for the provision of comprehensive HIV primary health care services.

HRSA has capped the number of Title III providers funded in each state. As a result, ensuring access to HIV-related primary care has become a greater challenge. When a new Title III program was funded in Lynchburg, it created sequential funding shifts in the northwest and southwest regions of the state. The direct result has been a reduction in funding for the Roanoke area that will impact access to primary medical care. Specifically, Carilion lost over $470,000 in Title III funds during the last year. Over the next year, Carilion will lose $107,000. The estimated annual cost to maintain HIV-related primary care services in Southwest Virginia is $577,000.

TITLE IV

Although all RWCA programs are required to serve women, infants, children, and youth living with HIV, Title IV provides funding to specifically address the needs of these populations. Title IV originated from the Pediatric AIDS Demonstration Program from 1988. In 1994, it was incorporated into RWCA. Title IV may fund a variety of services including:

- Primary and specialty medical care;
- Psychosocial services;
- Logistical support and coordination; and
- Outreach and case management.

A special component of Title IV involves identifying HIV-positive pregnant women and connecting them with services that can improve health outcomes for both mother and child. In addition, funds may be used to enhance client access to care and to clinical trials and research.

According to the Kaiser Family Foundation, in FY 2004, $65,197,603 was allocated by the federal government for Title IV. Virginia received $819,039 of these funds. Funding resources from HRSA show that Title IV funding has marginally decreased since FY 2003. HRSA distributes these funds through a competitive grant process in three-year cycles to organizations, such as community and faith-based

organizations, medical schools, children's hospitals, and state and community health departments.

OTHER FUNDING UNDER RWCA

Funding through the RWCA is available through additional programs not included in the four titles. The programs include:

- AIDS Education and Training Centers Program;
- Dental Reimbursement Program;
- Special Projects of Nations Significance (SPNS); and
- Community-Based Dental Partnership Program (CBDPP).

The AIDS Education and Training Centers Program is designed to support a network of more than ten regional centers. These centers are responsible for conducting targeted, multi-disciplinary education and training programs for health care providers treating individuals with HIV/AIDS. Trainings are targeted to providers who serve minority populations, the homeless, rural communities, incarcerated individuals and RWCA funded sites. In FY 2004, $29,397,862 in federal funds was allocated nationally to this program, but Virginia did not receive funding.

The Dental Reimbursement Program supports access to oral health care for individuals with HIV/AIDS. The program does so by reimbursing dental education programs for non-reimbursed costs incurred in providing such care. Eligible entities are limited to dental schools, post-doctoral dental education programs, and dental hygiene education programs that are accredited by the Commission on Dental Accreditation and have documented non-reimbursed costs incurred in providing oral health care to HIV positive individuals. Grantee funds may cover diagnostic, preventative, oral health education and health promotion, restorative, periodontal, prosthodontic, endodontic, oral surgery, and oral medicine services. Congress funded this program at $12,689,527 in FY 2004 but Virginia did not receive funding.

The Special Projection of National Significance (SPNS) program supports the creation of innovative HIV/AIDS service delivery models that have the potential for replication. Specifically, SPNS is the research and development component of RWCA. SPNS receives its funding through a percentage of Title I, Title II base, Title III, and Title IV funds up to $25 million. Funding in FY 2004, almost reached this level at $24,074,432. Virginia did not receive SPNS funding.

The Community-Based Dental Partnership Program (CBDPP) funds eligible dental schools, postdoctoral dental education programs, and dental hygiene programs in order to increase access to oral health care for unserved and underserved rural and urban HIV positive populations. Grants are provided for a period of up to three years in community settings. Programs that receive funding are to be a collaborative effort between the eligible entity and community-based dental providers. In FY 2004, $3,034,626 was allocated on the federal level for this program. Funding was not received in Virginia.

VI. Policy Options

The following Policy Options are offered for consideration by the Joint Commission on Health Care. They do not represent all available actions that the Joint Commission may wish to recommend regarding federal funding of HIV/AIDS prevention and treatment programs.

Option I: Take no action.

Option II: Introduce a budget amendment (language and funding) to expand the HIV resistance testing program.

a) $265,110 GFs; or
b) other level of funding.

Option III: Introduce a budget amendment (language and funding) to cover federal rescissions in prevention funding.

a) $285,000 GFs; or
b) other funding level.

Option IV: Introduce a budget amendment (language and funding) to cover the federal unfunded mandate, Advancing HIV Prevention Initiative.

a) $164,000 GFs; or
b) other amount of funding.

Option V: Introduce a budget amendment (language and funding) to stabilize access to HIV primary care services in Northern and Southwest Virginia.

a) $1,077,000 GFs (NOVA $500,000, SWVA $577,000); or
b) different amount of funding.

Option VI: Introduce a budget amendment (language and funding) to provide additional funding to offset projected ADAP shortfall.

a) $4,300,000 GFs;
b) $3,800,000 GFs ($4.3 million offset by SPAP of $500,000); or

c) other funding level.

Option VII: Introduce a budget amendment (funding and language) to create a SPAP to serve former ADAP Medicare Part D eligible clients.

a) $500,000 GFs; or
b) other amount of funding.

Option VIII: Introduce a resolution, encouraging the Virginia Commonwealth University School of Dentistry to investigate and if appropriate apply for funding under the RWCA Dental Reimbursement Program and the Community-Based Dental Partnership Program.

Option IX: Continue to monitor activities involving RWCA and federal funding by including the issues on the JCHC workplan for 2006.

APPENDIX A

ITEM 1.		Item Details($) First Year FY2005	Item Details($) Second Year FY2006	Appropriations($) First Year FY2005	Appropriations($) Second Year FY2006
	Joint Commission on Health Care (844)				
11.	Health Research, Planning, and Coordination (40600).....			$443,502	$443,882
	Health Policy Research (40606).....	$443,502	$443,882		
	Fund Sources: General.....	$443,502	$443,882		
	Authority: Title 30, Chapter 18, Code of Virginia.				
	A. The Joint Commission on Health Care should support the continuation of state funding of local initiatives to address the needs of adults and juveniles with mental health, mental retardation, or co-occurring disorders who come into contact with the criminal justice system.				
	B. The Joint Commission shall study recent trends in federal funding from the Ryan White C.A.R.E. Act and other federal funding to Virginia's HIV/AIDS prevention and treatment programs, and shall identify the impact on Virginia's current system of care delivery to persons living with HIV/AIDS. A report shall be made to the Joint Commission in accordance with the Joint Rules Committee schedule for consideration by the 2006 Session of the General Assembly.				

APPENDIX B

Medicaid Home and Community Based Services Waivers

Generally Medicaid services must be available in the same amount, duration, and scope to everyone on Medicaid, and individuals must be able to choose their own providers. Waivers allow states to "waive" some or all of those requirements.

Home and Community Based Services (HCBS) Waivers (§ 1915 (c) of SSA)

- Can waive statewideness.
- Can waive comparability of services.
- Can waive community income and resource rules.
- Can waive rules that require States to provide services, on an equal basis, to all persons in the State.
- States have the flexibility to design each waiver and select the mix of services that best meets the needs of the population they wish to serve.
- May be provided statewide or may be limited to specific geographic subdivisions.
- Waivers can be targeted to specific groups or any subgroup thereof that the State may define: aged or disabled, or both; mentally retarded or developmentally disabled or both; and mentally ill. Cannot be targeted to people in an Institution for Mental Disease (IMD). States cannot get waivers with an alternate institutional placement of an Institution for Mental Disease (IMD). Medicaid does not pay for any services for people in IMDs who are between the ages of 21 through 64.
- Initially approved for 3 years and renewed every 5 years.
- Optional programs that afford States the flexibility to develop and implement alternatives to institutionalizing Medicaid eligible individuals.
- The program recognizes that many individuals who would otherwise be institutionalized can be cared for in their homes and communities at a cost no higher than that of institutional care when compared on an average basis. This does not mean that waivers are a cost-savings to States since many people who would not enter an institution will choose community care. The bottom line is that waivers can be costly to states.
- To receive approval to implement a waiver, a State Medicaid agency must assure the Centers for Medicare and Medicaid Services (CMS) that it will not cost more, on average, to provide home and community based services than providing institutional care would cost. Waiver recipients must be offered the choice of institutional or community placement. The average costs of individuals on the waiver are compared to the average costs of individuals in the institution.
- The State must also assure CMS that there are safeguards to protect the health and welfare of recipients.

- Waivers must be submitted by the single state Medicaid agency (DMAS). The single state agency must not delegate, to other that its own officials, authority to:

  ☑ exercise administrative discretion in the administration or supervision of the plan, or

  ☑ issue policies, rules, and regulations on program matters.

  ☑ The authority of the agency must not be impaired if any of its rules, regulations, or decisions are subject to review, clearance, or similar action by other offices or agencies of the State.

  ☑ If other State or local agencies or offices perform services for the Medicaid agency, they must not have the authority to change or disapprove any administrative decision of that agency, or otherwise substitute their judgment for that of the Medicaid agency with respect to the application of policies, rules, and regulations issued by the Medicaid agency. 42 C.F.R. 431.10.

The Commonwealth of Virginia Had Six HCBS Waivers in FY 2004:

1. AIDS Waiver

2. Consumer Directed Personal Attendant Services (CD-PAS) Waiver (In February, 2005 the CD-PAS and Elderly and Disabled Waivers were combined into the Elderly or Disabled with Consumer-Direction Waiver (EDCD))

3. Elderly and (or) Disabled (E&D) Waiver

4. Individual and Family Developmental Disabilities Support Waiver (DD Waiver).

5. Mental Retardation Waiver (MR)

6. Technology Assisted Waiver (Tech)

As of July 1, 2005, Virginia had six waivers, which included the AIDS, DD, EDCD, MR, and Tech Waivers, and a Day Support Waiver for people with Mental Retardation (300 slots), which became effective July 1, 2005. An additional waiver, the Alzheimer's Assisted Living Waiver (200 slots), was approved by CMS effective July 1, 2005, but was not yet operational since State regulations were not yet in place. This waiver is expected to be operational in the fall of 2005.

AIDS Waiver

Initiative	Purpose is to provide care in the community rather than in nursing facilities or hospitals.
Targeted Population:	Diagnosis of AIDS or AIDS Related Condition (ARC) and documentation that the individual is experiencing medical and functional symptoms associated with AIDS or ARC which would require nursing facility or hospital care
Eligibility Rules	Must be eligible for Medicaid and meet screening criteria; income limit is 300% of the SSI payment limit for one person ($1,737/month). No patient pay.
Services Available	• Case management • Nutritional supplements • Private duty nursing • Personal care (consumer or agency directed) • Respite care
Service Authorization	Local and hospital screening teams
Program Administration	Program administered by DMAS
Service Provision	Services are provided by case management providers or personal care and nursing agencies that have a provider agreement with DMAS.
Number of People Served	274 people were served in FY 2004.
Cost	Waiver costs were $608,497 in FY '04. Other costs for people on the Waiver were $6,117,320 ($4 million was for pharmacy)

Consumer Directed Personal Attendant Services Waiver

Initiative	Purpose is to provide care in the community rather than in a nursing facility.
Targeted Population:	Individuals 65 or older or who are disabled, who meet screening criteria and are at imminent risk of nursing facility placement. Individuals must be able to hire, train and fire, if necessary, their own attendants, or have a parent, spouse, legal guardian, or adult child who directs care on their behalf if they cannot do so.
Eligibility Rules	Must be eligible for Medicaid and meet screening criteria; income limit is 300% of the SSI payment limit for one person ($1,737 /month). Could have a patient pay if income is in excess of SSI income limit for one ($579). Due to expenses of employment, can keep additional amount of earned income if working more than 8 hours/ week.
Services Available	Personal attendant services
Service Authorization	Local and hospital screening teams
Program Administration	Program administered by DMAS
Service Provision	Personal attendants hired by the recipient. Service coordination is provided by registered nurses, social workers or case managers who have a provider agreement with DMAS. Service coordinators assess, develop and monitor the care plan.
Number of People Served	417 people were served in FY 2004
Cost	The cost of waiver services was $4,403,107 in FY '04; the cost of acute care services was an additional $2,334,535.

Elderly and (or) Disabled Waiver

Initiative	Purpose is to provide care in the community rather than in a nursing facility.
Targeted Population:	Individuals 65 or older or who are disabled and who meet screening criteria and are at imminent risk of nursing facility placement (42 CFR 441.302(c)(1).
Eligibility Rules	Must be eligible for Medicaid and meet screening criteria; income limit is 300% of the SSI payment limit for one person ($1,737 month). Could have patient pay if income is in excess of SSI income limit for one ($579).
Services Available	• Adult day health • Respite care • Personal care • Personal Emergency Response System
Service Authorization	Local and hospital screening teams
Program Administration	Program administered by DMAS
Service Provision	Services are provided by personal care and nursing agencies that have a provider agreement with DMAS.
Number of People Served	In FY 2004, 10,161 people were served.
Cost	Waiver expenditures for FY 2004 were $101,354,887 Other costs for Waiver recipients were $78,082,480

Individual and Family Developmental Disabilities (DD) Support Waiver

Revised 8/7/2005

Initiative	Home and Community Based (1915(c)) waiver whose purpose is to provide care in the community rather than in an Intermediate Care Facility for the Mental Retarded (ICF/MR).
Targeted Population:	Individuals who are 6 years of age and older who have a related condition and do not have a diagnosis of mental retardation who (1) meet the ICF/MR level of care criteria (i.e., they meet two out of seven levels of functioning in order to qualify); (2) are determined to be at imminent risk of ICF/MR placement, and (3) are determined that community-based care services under the waiver are the critical services that enable the individual to remain at home rather than begin placed in an ICF/MR.
Eligibility Rules	Individual Eligibility An individual is deemed eligible for DD Waiver services based on three factors: ➢ **Diagnostic Eligibility**: Individuals age six and older must have a psychological or standardized developmental evaluation that states that the child does not have a diagnosis of mental retardation or is at developmental risk and reflects the child's current level of functioning. ➢ **Functional Eligibility**: All individuals receiving DD Waiver services must meet the ICF-MR (Intermediate Care Facility for Mental Retardation) level of care. This is established by meeting the indicated dependency level in two or more of the categories on the "Level of Functioning Survey." ➢ **Financial Eligibility**: An eligibility worker from the local Department of Social Services (DSS) determines an individual's financial eligibility for Medicaid. Some individuals who would not ordinarily qualify financially for Medicaid may be eligible by receipt of DD Waiver services. Medicaid regulations specify that, once an individual has been determined eligible by the IFDDS screening team, he or she must be offered a choice between institutional and Waiver services.
Services Available	• **Case management**: is the assessment, planning, linking and monitoring for individuals referred for the DD Waiver. It also ensures the development, coordination, implementation, monitoring, and modification of consumer service plans; links individuals with appropriate community resources and supports;

coordinates service providers; and monitors quality care.

- **In– Home Residential Support Services**: training, assistance and specialized supervision, provided primarily in an individual's home to help the person learn or maintain skills in activities of daily living, safety in the use of community resources, and behavior appropriate for home and the community.
- **Day support**: training, assistance and specialized supervision to enable the individual to acquire, retain or improve his/her self-help, social and adaptive skills. These services typically take place away from the home in which the individual resides and may be located in a "center" or in community locations.
- **Supported employment**: supports to enable individuals with disabilities to work in settings in which persons without disabilities are typically employed. It may be provided to one person in one job (e.g., a person working to bus tables in a restaurant) or to several people at a time when those individuals are working together as a team to complete a job (e.g., such as a grounds maintenance crew).
- **Prevocational services**: training and assistance to prepare an individual for paid or unpaid employment. These services are not job task-oriented. These are for individuals who need to learn skills fundamental to employment such as accepting supervision, getting along with co-workers, using a time clock, etc.
- **Personal assistance**: direct support with activities of daily living (e.g., bathing, toileting, personal hygiene skills, dressing, transferring, etc.), instrumental activities of daily living (e.g., assistance with housekeeping activities, preparation of meals, etc.), accessing the community, taking medication or other medical needs, and monitoring the individual's health status and physical condition. These services may be agency-directed or *consumer-directed.*
- **Respite**: services designed to provide temporary, substitute care for that which is normally provided by the family or other unpaid, primary caregiver of an individual. These short-term services may be provided because of the primary caregiver's absence in an emergency or on-going need for relief. These services may be agency-directed or *consumer-directed.*
- **Companion**: provide non-medical care, socialization or support to adults in an individual's home or at various locations in the community. These services may be agency-directed or *consumer-directed.*

- **Consumer-directed services:** offer the individual/family the option of hiring workers directly, rather than using traditional agency staff.

- **Assistive technology**: specialized medical equipment, supplies, devices, controls and appliances, which enable the individual to better perform activities of daily living, to perceive, control or communicate with his/her environment, or which are necessary to his/her proper functioning.

- **Environmental modifications**: physical adaptations to an individual's home or vehicle needed by the individual to ensure his/her health, welfare and safety or enable him/her to experience greater independence in the home and around the community.

- **Skilled nursing services**: nursing services ordered by a physician for individuals with serious medical conditions and complex health care needs. This service is available only for individuals for whom these services cannot be accessed through another means. These services may be provided in an individual's home, community setting, or both.

- **Therapeutic consultation**: expert training and technical assistance in any of the following specialty areas to enable family members, caregivers, and other service providers to better support the individual. The specialty areas are: Psychology, Social Work, Speech and Language Pathology, Occupational Therapy, Physical Therapy, Therapeutic Recreation, Psychiatric Clinical Nursing, and Rehabilitation.

- **Crisis stabilization**: direct intervention (and may include one-to-one supervision) to a person with developmental disabilities who is experiencing serious psychiatric or behavioral problems which jeopardize his/her current community living situation.

- **Personal emergency response systems** (PERS): an electronic device that enables the individual who is alone to access a centralized, staffed emergency center in the event of an emergency.

- **Family and Caregiver:** training will provide training and counseling services to families of individuals receiving services in the DD Waiver

Service Authorization — An individual or family/caregiver submits a "Request for Screening"

	form screening team . The screening request is taken to one of the 11 Child Development Clinics designated to serve as the screening team for the DD Waiver. If the screening team determines the individual meets criteria, a service plan is created and DMAS assigns a slot to the individual once a slot becomes available.
Program Administration	The program is administered by the Department of Medical Assistance Services (DMAS). DMAS also conducts preauthorization of DD Waiver services.
Number of People Served	FY2004 392

Waiting List

A waiting list does exist for the DD Waiver. The waiting list is maintained on a first-come, first served basis. Individuals are assigned waiting list numbers based on the date DMAS receives the Screening Packet from the screening.

If an individual is determined eligible, a case manager works with the individual to develop a Plan of Care (POC). The amount of the POC determines which level waiting list the individual is assigned. Individuals whose care plans are below $25,000 are assigned to Level I. Individuals whose care plans exceed $25,000 are assigned to Level II.

Emergency Criteria

Subject to available funding, individuals must meet at least one of the emergency criteria to be eligible for immediate access to waiver services without consideration to the length of time an individual has been waiting to access services. In the absence of waiver services, the individual would not be able to remain in his home.

A. The criteria are:

1. The primary caregiver has a serious illness, has been hospitalized, or has died; or
2. The individual has been determined by the DSS to have been abused or neglected and is in need of immediate Waiver services; or
3. The individual has behaviors which present risk to personal or public safety; or
4. The child presents extreme physical, emotional or financial burden at home and the family or caregiver is unable to continue to provide care.

Providers:

An institution, facility, agency, partnership, corporation, or association that meets the standards and requirements set forth by DMAS, and has a current, signed contract with DMAS to be a provider of DD Waiver services.

Accessing DD Waiver Services

- Individual, family or representative requests services from the Case Manager.

- The case manager determines the preferred services and necessary supports by meeting with the individual and family (or other caregivers) and confirms diagnostic and functional eligibility by obtaining a psychological evaluation and completing an ICF/MR Level of Functioning Survey (LOF).

- Once the individual is determined eligible (including financial eligibility through the Department of Social Services), the case manager informs the individual and family of the full array of DD Waiver services and documents the individual's choice of Waiver or institutional care.

- Once it is determined that a slot is available and the individual has been enrolled, the individual selects providers for needed services. The case manager coordinates the development of a Consumer Service Plan (CSP) with the individual, family or other caregivers and the service providers within 60 days of enrollment. The CSP includes all of the supporting documentation developed by this team and describes the services that will be rendered.

- Prior to the start of services, the case manager forwards appropriate documentation to DMAS staff for review and authorization of the requested DD Waiver services.

- Once approved, DMAS staff enters service data in the DMAS computer system. This generates a notification letter to the providers and permits them to bill for approved services. Service provision should commence within 60 days from enrollment.

For additional information, please contact Ms. Pat Arevalo, Supervisor, Behavioral Health and Developmental Disabilities Unit of DMAS, at (804) 786-1465 or by e-mail at Pat.arevalo@dmas.virginia.gov.

Mental Retardation Waiver

Initiative	Purpose is to provide care in the community rather than in an Intermediate Care Facility for the Mentally Retarded.
Targeted Population	Individuals with mental retardation or related conditions and individuals under the age of 6 at developmental risk who have been determined to require the level of care provided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR).
Eligibility Rules	Must be eligible for Medicaid and meet screening criteria; income limit is 300% of the SSI payment limit for one person ($1,737/month). Could have a patient pay if income is in excess of SSI income limit for one ($579). Could have a patient pay if income is in excess of SSI income limit for one ($579). Due to expenses of employment, can keep additional amount of earned income if working more than 8 hours/ week.
Services Available	• Day support • Supported employment • Residential supports (Congregate and In-Home) • Therapeutic consultation • Personal assistance services (consumer or agency directed) • Respite care (consumer or agency directed) • Skilled nursing services • Crisis Stabilization • Environmental Modifications • Assistive Technology • Companion (consumer or agency directed)
Service Authorization	Community Mental Health Services Boards (CSB)
Program Administration	Program administered by DMAS and DMHMRSAS
Service Provision	Services are provided by providers who have an agreement with DMAS.
Number of People Served	5,622 people were served during FY 2004. There is a waiting list for services.
Cost	Waiver costs were $227,229,982 in FY '04. Other costs for people on the waiver were $78,821,941.

Technology Assisted Waiver

Initiative	Purpose is to provide care in the community rather than in a nursing facility (adults) or hospital (children).
Targeted Population:	Individuals who need both a medical device to compensate for the loss of a vital body function and substantial and ongoing skilled nursing care.
Eligibility Rules	Must be eligible for Medicaid and meet screening criteria; income limit is 300% of the SSI payment limit for one person ($1,737/month). Could have a patient pay if income is in excess of SSI income limit for one ($579).
Services Available	• Private duty nursing • Respite care • Durable medical equipment • Personal care • Environmental modification
Service Authorization	Health Care Coordinator who is either an employee of DMAS or a DMAS contractor
Program Administration	Program administered by DMAS
Service Provision	Case management is provided by DMAS staff. Nursing services are provided by nursing agencies that have a provider agreement with DMAS.
Number of People Served	339 served in FY 2004
Cost	The cost of waiver services was $19,648,061 in FY '04; the cost of acute care services was an additional $7,109,713.

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