

THE BASICS

MARCH 10, 2010

The Ryan White HIV/AIDS Program

There are an estimated 1.1 million people in the United States living with human immunodeficiency virus (HIV) and its disease progression, acquired immunodeficiency syndrome (AIDS). Despite prevention efforts, an estimated 56,300 new individuals were infected with HIV in the United States in 2006, the most recent year for which data are available. Nearly 30 years after the identification of the disease, there is no approved vaccine or cure for HIV/AIDS but it can be treated with highly active anti-retroviral therapy (HAART), which slows the progression of HIV to AIDS. For those with access to it through private or public health insurance or other programs, HAART can transform the effects of the virus so that the illness becomes a chronic condition, rather than a terminal one.

HIV/AIDS disproportionately impacts certain populations, creating alarming levels of death and disability. African American males have the highest rates of HIV infection. In 2006, the HIV diagnosis rate for all African American males was more than seven times that for White males, more than twice the rate for Hispanic males, and more than twice the rate for African American females. HIV infection rates among African American females are disproportionately high. In 2006, the HIV diagnosis rate for African American females was more than 19 times the rate for White females. In 2006, HIV disease was the sixth leading cause of death among persons 24 through 44 years old, after unintentional injury, cancer, heart disease, suicide, and homicide. It was the fourth leading cause of death for African American males and females aged 25 through 34, and the fourth leading cause of death among Hispanic males and females aged 35 through 44.2 The largest transmission category for people living with HIV/ AIDS consists of men who have sex with men.3

National Health Policy Forum

2131 K Street, NW Suite 500 Washington, DC 20037

T 202/872-1390 **F** 202/862-9837 **E** nhpf@gwu.edu www.nhpf.org Medicaid and the Ryan White HIV/AIDS Program are the two key federal programs that fund treatment for low-income, uninsured, and underinsured people living with HIV/AIDS.⁴ The Ryan White Program provides funding to metropolitan areas, states, and community-based organizations through awards and grants; it is not health insurance. Ryan White funds pay for **core medical services**, defined as outpatient and ambulatory medical services, medications, mental health and substance abuse services, oral health care, hospice care, early intervention services, health insurance premium and cost sharing assistance, medical nutrition therapy, home health care, and **support services** such as transportation, respite care, outreach, and language services.

Unlike Ryan White, Medicaid is health insurance and provides a broader array of medical services including inpatient care and long-term care services. There is limited eligibility for Medicaid for persons living with HIV that has not progressed to AIDS. Often the only avenue of eligibility, no matter how poor a person may be, is through a total disability determination by the Social Security Administration and therefore eligibility for Supplemental Security Income (SSI), which in some states automatically qualifies a person for Medicaid.

As a discretionary program—not an entitlement like Medicaid—Ryan White funds are finite, so services are provided while funds last. Ryan White funds serve an estimated 529,000 people per year, the majority of whom live below the federal poverty line and are ethnic and racial minorities.

The Ryan White HIV/AIDS Program is authorized as Title XXVI of the Public Health Service Act. Congress created it in 1990 and reauthorized the program in 1996, 2000, 2006, and 2009. The most recent reauthorization, the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87), extended the program for four years, through September 30, 2013. The authorizing committees of jurisdiction are the Senate Committee on Health, Education, Labor, and Pensions and the House of Representatives Committee on Energy and Commerce. Congress appropriated \$2.3 billion for Ryan White in fiscal year (FY) 2010; the Health Resources and Services Administration (HRSA) within the Department of Health and Human Services (DHHS) administers the program.

The National Health Policy Forum is a nonpartisan research and public policy organization at The George Washington University. All of its publications since 1998 are available online at www.nhpf.org.

RYAN WHITE PROGRAM COMPONENTS

Part A

Part A of the Ryan White HIV/AIDS Program awards funds to **eligible metropolitan areas (EMAs)**, defined as areas that have a population of at least 50,000 and a cumulative total of more than 2,000 reported AIDS cases within the past five years, and to **transitional grant areas (TGAs)**, defined as areas with a population of at least 50,000 with a cumulative total of 1,000 to 1,999 reported AIDS cases within the past five years.⁵

Two-thirds of Part A funds are distributed through **formula awards** and the remaining third through competitive **supplemental grants** on the basis of the severity of need. Funds are directed to the chief elected official (CEO) of the EMA. The CEO is required to appoint a local planning council that has broad representation and has responsibility for assessing needs, setting service priorities, and directing the CEO to purchase medical and support services to meet the needs of the local population living with HIV/AIDS. While TGAs are not required to have planning councils, they are required to utilize a community planning process in determining how these funds should be used.

Until the 2006 reauthorization, Ryan White formula funds were distributed on the basis of AIDS case data. Case data is collected through surveillance systems that were historically either codebased or name-based surveillance systems. Name-based HIV reporting has been recommended by the Centers for Disease Control and Prevention (CDC) since 2005 for all states and territories to avoid double counting of cases, but some states kept code-based systems because of concerns about client confidentiality. The 2006 reauthorization made two significant changes related to case data: it mandated the distribution of funds based on HIV and AIDS data in an effort to target funding to the epidemic of HIV cases before they progress to AIDS, and it mandated a time table for states to transition to name-based HIV surveillance systems. Currently all states have name-based HIV surveillance systems in place, but some are still maturing. Recognizing this, the 2009 reauthorization continues funding through FY 2012 to those jurisdictions with reporting systems that are not yet mature. For funding purposes, the HIV case counts from states with immature systems will be reduced by 5 percent for FYs 2010 and 2011 and 6 percent

for 2012. In addition, grant amounts for successive years are limited to no more than a 5 percent increase over the previous year. Only name-based case data will be accepted beginning in FY 2013.

With the move to funding that is based on HIV and AIDS cases in 2006, there was concern that a number of states and localities would experience significant funding shifts that would disrupt care for people living with HIV/AIDS. To ameliorate these shifts, the 2006 reauthorization created hold harmless provisions to ensure that an EMA does not receive a formula award that is less than a specified percentage of what it received in the base year. The 2009 reauthorization retains hold harmless provisions, ensuring that in FY 2010 EMAs will receive 95 percent of the sum of the FY 2009 formula award and FY 2009 hold harmless amount and, for FYs 2011 and 2012, 100 percent of the sum of the FY 2010 formula award and FY 2010 hold harmless amount. For FY 2013, EMAs will receive 92.5 percent of the sum of the FY 2012 formula award and the FY 2012 hold harmless amount. Hold harmless provisions are funded through the one-third of Part A funds that are set aside for supplemental grants.

Though not a part of the program's authorization, **stop loss** provisions in appropriations bills for fiscal years 2008, 2009, and 2010 have affected the distribution of Part A funds. In general, the provisions set aside Part A funds to make up for losses to certain areas that resulted from the implementation of provisions of the 2006 reauthorization.⁶

Part B

Part B consists of four components—base, supplemental, base AIDS Drug Assistance Program (ADAP), and supplemental ADAP—which are designed to allocate resources on the basis of relative need.⁷

The Part B **base award** formula provides funds to states and the District of Columbia, Puerto Rico, the U.S. Virgin Islands, the Republic of the Marshall Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Federated States of Micronesia, and the Republic of Palau. The formula consists of three components: 75 percent is based on the state's proportion of total HIV/AIDS cases compared with the total U.S. HIV/

AIDS cases, 20 percent is based on the state's proportion of HIV/AIDS cases outside EMAs and TGAs, and 5 percent is based on the state's proportion of HIV/AIDS cases in states with no Part A funding. At least 75 percent of funds must be spent on core medical services, and up to 25 percent may be spent on support services. A competitive **supplemental grant program** exists for those states with a demonstrated need for additional assistance.

About one-quarter of total Ryan White funding—\$835 million in FY 2010—is earmarked by Congress for AIDS Drug Assistance Programs (ADAPs). States receive ADAP funds on the basis of their proportion of living HIV/AIDS cases compared with the total number of cases in the United States. In addition to the federal grant, many ADAPs receive state general revenue funding and funds from rebates negotiated with drug manufacturers.

ADAPs operate in all jurisdictions that receive base formula awards, except the Republic of Palau. To receive services from an

ADAP, jurisdictions must ensure that an individual has been diagnosed with HIV and that he or she qualifies as "low income," as defined by the jurisdiction. Grantees primarily provide prescription drugs approved by the Food and Drug Administration to eligible individuals, but they may also use funds to purchase health insurance for eligible clients if that coverage includes a prescription drug benefit equal to or greater than that of the state-run ADAP, and for services that enhance access to, adherence to, and monitoring of drug treatments. Five percent of the ADAP appropriation is set aside for competitive supplemental **ADAP grants** for those jurisdictions with a severe need to increase availability of HIV/AIDS drugs.

The 2009 reauthorization **hold harmless** provision that created a

RYAN WHITE FUNDING BY PART, FISCAL YEAR 2010

PART*	FUNDING TYPES	APPROPRIATION
A	Formula awards to eligible metropolitan areas and transitional grant areas; competitive supplemental grants	\$679.1 million
В	Formula base awards; competitive supplemental grants; emerging communities awards	\$418.8 million
	AIDS Drug Assistance Program (ADAP) base awards; ADAP competitive supplemental grants	\$835.0 million
С	Competitive grants for early intervention services, planning, and capacity development	\$206.8 million
D	Competitive grants for programs serving women, infants, children, and youth	\$77.8 million
F	AIDS Education and Training Centers	\$34.8 million
	Dental Programs	\$13.6 million
TOTAL		\$2.3 billion

^{*} No funds have been appropriated for Part E.

transition period for states with immature name-based HIV surveillance systems (as described under Part A) applies to Part B grants as well. In FY 2010, Part B grantees will receive 95 percent of the FY 2009 formula and ADAP award; for FYs 2011 and 2012, 100 percent of the FY 2010 formula and ADAP award; and for FY 2013, 92.5 percent of the FY 2012 formula and ADAP award. Hold harmless provisions are funded out of the one-third of Part B funds (non-ADAP) set aside for supplemental grants and any unobligated funds repaid by the states.

In addition to the four components, Part B also awards **emerging community** grants for the provision of HIV-related services in those metropolitan areas with 500 to 1,000 reported AIDS cases over the last five years. Funds are distributed based on the number of the emerging community's living HIV/AIDS cases relative to all living HIV/AIDS cases in emerging communities nationwide.

PART C

Whereas the first two parts of the Program fund metropolitan areas and states mainly through formula awards, Part C provides funds to community-based organizations through a competitive grant application process. Eligible organizations include public and private nonprofit organizations; primary care providers such as federally qualified health centers, local health departments, hemophilia treatment centers, rural health clinics, Indian Health Service facilities; and outpatient facilities at academic medical centers that serve people living with HIV/AIDS. The 2006 law stipulated that at least 75 percent of funds must be used to provide core medical services, and at least half of those services must be early intervention services. Early intervention services include counseling, HIV testing, referrals, and other clinical and diagnostic services related to HIV/AIDS.⁸

PART D

Part D provides funds for family-centered care for women, infants, children, and youth with HIV/AIDS. Grants are awarded competitively to public and private nonprofit organizations to provide outpatient or ambulatory care, case management, referrals for inpatient care, substance abuse and mental health services,

support services, outreach, and access to clinical trials and clinical research. A special focus of Part D is to identify HIV-positive pregnant women and ensure that they have access to prenatal care to prevent mother-to-child transmission of the virus. There is no statutory set-aside of funds for core medical services in Part D; Part D program funds are not required to be used for primary care services if those services are paid for by other sources like Medicaid or the Children's Health Insurance Program.⁹

PART E

Part E includes a number of provisions about coordination of federal HIV programs, audits of grantees, definitions, and prohibitions on use of funds. No funds have been appropriated for Part E.

PART F

Part F includes the AIDS Education and Training Centers (AETC) Program, two dental programs, and the Special Projects of National Significance Program, all of which are competitively awarded. AETC is the clinical training component of the Act that provides funding for national and regional centers that conduct multidisciplinary training and education programs for health care providers who treat patients with HIV/AIDS. The Ryan White Dental Reimbursement Program reimburses dental schools, postdoctoral dental programs, and dental hygiene programs for the uncompensated services they provide to people living with HIV/ AIDS. The Community-Based Dental Partnership Program works to increase access to oral health care services for people living with HIV while providing education and clinical training for dental care providers, especially those in community-based settings. The Special Projects of National Significance Program is designed to address the emerging needs of Ryan White clients and to assist in the development of a standard electronic client information data system to improve grantee reporting of client-level data. The Minority AIDS Initiative (MAI) addresses the disproportionate impact of HIV/AIDS on racial and ethnic minorities. MAI funding is woven throughout the various Parts of the program. The 2006 reauthorization shifted the funding from formula-based to competitive for Parts A and B. The 2009 reauthorization reverted the

competitive MAI funding to formula funding based on the distribution of HIV/AIDS cases among racial and ethnic minorities.¹⁰

ENDNOTES

- H. Irene Hall *et al.*, "Estimation of HIV Incidence in the United States," *Journal of the American Medical Association*, 300, no. 5 (August 6, 2008): pp. 520–529
- 2. CDC, "Deaths Among Persons with AIDS through 2006," from *HIV/AIDS Surveillance Supplemental Report*, 14, no. 3 (2009); available at www.cdc.gov/hiv/topics/surveillance/resources/reports/2009supp_vol14no3/default.htm.
- For more information on the HIV/AIDS epidemic in the United States, see the HIV/AIDS section of the Centers for Disease Control and Prevention's (CDC's) Web site at www.cdc.gov/hiv/default.htm.
- 4. Medicare is the largest federal payer for HIV/AIDS treatment. Of the approximately 100,000 people with HIV on Medicare, 93 percent are under age 65 and qualify because they are disabled and receiving Social Security Disability Insurance (SSDI) payments. For more information see Kaiser Family Foundation, "HIV/AIDS Policy Fact Sheet: Medicare and HIV/AIDS," February 2009; available at www.kff.org/hivaids/upload/7171_04.pdf.
- 5. For more information on Part A including a list of eligible metropolitan areas (EMAs) and transitional grant areas (TGAs) see the HRSA HIV/AIDS Bureau's Web site at http://hab.hrsa.gov/treatmentmodernization/parta.htm.
- 6. The U.S. Government Accountability Office (GAO) has written a number of reports on the impact of these provisions, including "Ryan White Care Act: Impact of Legislative Funding Proposal on Urban Areas," GAO-08-137R, October 5, 2007, available at www.gao.gov/new.items/d08137r.pdf; "Ryan White CARE Act: Estimated Effect of Proposed Stop-Loss Provision on Urban Areas," GAO-09-472R, March 9, 2009, available at www.gao.gov/new.items/d09472r.pdf; and "Ryan White CARE Act: Estimated Effect of Proposed Stop-Loss Provision in H.R. 3293 on Urban Areas," GAO-09-947R, August 7, 2009, available at www.gao.gov/new.items/d09947r.pdf.
- 7. For more information on Part B see HRSA, "Part B—Grants to States and Territories"; available at http://hab.hrsa.gov/treatmentmodernization/partb.htm.
- 8. For more information on Part C see HRSA, "Part C—Early Intervention Services"; available at http://hab.hrsa.gov/treatmentmodernization/partc.htm.
- 9. For more information on Part D see HRSA, "Part D—Services For Women, Infants, Children, Youth and Their Families"; available at http://hab.hrsa.gov/treatmentmodernization/partd.htm.
- 10. For more information on Part F see http://hab.hrsa.gov/aboutus.htm.

FOR MORE INFORMATION SEE:

- Jessamy Taylor, "Caring for 'Ryan White': The Fundamentals of HIV/AIDS Treatment Policy," National Health Policy Forum, Background Paper, August 22, 2005; available at www.nhpf.org/library/background-papers/BP_RyanWhite_08-22-05.pdf
- The HIV/AIDS section of the Health Resources and Services Administration's Web site at http://hab.hrsa.gov/, as well as HIV/AIDS Bureau, "The Power of Connections: 2008 Ryan White HIV/AIDS Progress Report," Health Resources and Services Administration; available at http://hab.hrsa.gov/publications/progressreport08/2008ProgressReport.pdf.
- Kaiser Family Foundation, "HIV/AIDS Policy Fact Sheet: The Ryan White Program," February 2009, available at www.kff.org/hivaids/upload/7582_05.pdf.
- Judith A. Johnson, "The Ryan White HIV/AIDS Program," Congressional Research Service, order code RL33279, January 21, 2010.

Prepared by Jessamy Taylor.
Please direct questions to jrtaylor@gwu.edu.