



Forum Session Meeting Announcement

Tuesday, March 14, 2006
11:45am–12:15pm — Lunch
12:15pm–2:00pm — Discussion

Caring for “Ryan White”: Balancing Quality, Access, Equity, and Finite Resources

A Discussion Featuring:

Marcia Crosse, PhD

Director, Health Care Group
U. S. Government Accountability Office

Martin Shapiro, MD, PhD, MPH

Professor of Medicine and Professor of Health Services
University of California, Los Angeles

David Holtgrave, PhD

Professor and Chair of the Department of Health, Behavior and Society
Bloomberg School of Public Health
Johns Hopkins University

Location

**Rayburn House Office
Building**

Independence Avenue and
South Capitol Street, SE
Room 2123

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Caring for “Ryan White”: Balancing Quality, Access, Equity, and Finite Resources

OVERVIEW

This Forum session will focus on the evolution of both HIV/AIDS treatment and policies to make those care advancements available to low-income, uninsured people living with the disease through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Variation in access to treatment in cities and states across the country will be discussed as well as Ryan White’s role in that variation. Funding distribution mechanisms, questions of equity related to the distribution formulas, and the potential impact of changing those formulas through the reauthorization will be considered. The session will also explore the importance of diagnosing HIV early to prevent further infections and to limit future demands on publicly funded health care programs that treat low-income populations with HIV/AIDS.

For additional 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/pdfs_bp/BP_RyanWhite_08-22-05.pdf; and “The Basics: The Ryan White CARE Act,” *National Health Policy Forum, September 14, 2005*, available at www.nhpf.org/pdfs_basics/Basics_RyanWhite.pdf. ■

SESSION

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has provided funding to treat low-income, uninsured people living with HIV/AIDS since its enactment in 1990. The program’s statutory authority expired on September 30, 2005. Many consider the current reauthorization debate just another “formula fight,” but changes in the HIV/AIDS epidemic in the United States over the past five years and projections for the next five years demand a broader perspective and discussion.

HIV/AIDS has been part of the American landscape for 25 years, and the nation’s reaction to the disease, the people who live with it, and its treatment have evolved over the quarter century. Scientific advances have fundamentally changed HIV/AIDS from a death sentence to a chronic condition, albeit one that requires strict adherence to a rigorous prescription drug regimen. Given access to these costly drugs, people living with HIV can significantly delay or even prevent progression to AIDS.

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Close to 1.2 million people are estimated to be living with HIV/AIDS today. At least one-quarter of those infected, around 300,000 people, do not know they are infected with the disease. This subset of the HIV/AIDS population is thought to cause two-thirds of new infections each year. While HIV incidence—in other words, the number of new infections—has declined greatly from the early years of the epidemic, it has remained steady at about 40,000 per year over the last decade.¹ The increasing number of people living with HIV/AIDS creates greater risk for new infections in the absence of aggressive prevention and also escalates demands on the health care system.

HIV/AIDS burden is concentrated in segments of the U.S. population. Racial and ethnic minorities—especially African Americans—have been disproportionately affected by HIV/AIDS. Men who have sex with men remain the largest transmission group, but heterosexual transmission has increased significantly over time. Women account for about one-quarter of new AIDS diagnoses, up from 8 percent 20 years ago. AIDS cases have grown fastest in the South compared with other regions of the United States over time.

Data on the number of people with AIDS is relatively complete but it does not provide a real picture of the magnitude of the HIV/AIDS epidemic. Given appropriate treatment, the lag time between HIV infection and the progression to AIDS can be significant so focusing on AIDS cases solely provides an incomplete account. In addition, states collect and report HIV case data differently, making a true national HIV estimate impossible. The HIV case estimates by the Centers for Disease Control and Prevention (CDC) include data from 35 states and jurisdictions that have “mature” name-based HIV case reporting systems. The CDC accepts only name-based reports so it can detect duplication of reported cases across jurisdictions. Three of the top ten states in terms of cumulative AIDS cases—California, Illinois, and Maryland—do not use name-based reporting and are thus excluded from the CDC’s national HIV prevalence and incidence estimates.

Although treatment for HIV/AIDS has advanced tremendously since the start of the epidemic, many cannot afford to pay for it. Medicaid and the Ryan White CARE Act form the safety net of health care financing for low-income, uninsured, and disabled people living with HIV/AIDS. The CARE Act was authorized in 1990 as the number of people dying of AIDS surged and overwhelmed urban health care systems. It was reauthorized in 1996 and in 2000, and its most recent authorization expired in 2005. Each year, Medicaid provides care to about 230,000 people living with AIDS and Ryan White serves about 533,000 individuals and families living with HIV/AIDS.² Despite the availability of these key programs, the CDC estimates that about half of people with HIV/AIDS are not receiving regular care for their condition.

Ryan White is the payer of last resort when no other source of payment is available; Congress appropriated \$2.1 billion in fiscal year 2006 for Ryan

White programs. It fills the care gaps left when an individual is ineligible for Medicaid or Medicare, or cannot afford or is not eligible for private insurance. Its gap-filling nature means that Ryan White–financed care varies significantly across states and cities.

The four titles of the current statute fund: cities (Title I), states and emerging communities (Title II), and community-based organizations (Titles III and IV). Eighty-five percent of funds are distributed through Titles I and II. The bulk of Title II funds are distributed to states to fund their AIDS Drug Assistance Program (ADAP) that purchases and provides prescription drugs. In general, CARE Act monies are used to provide medical, mental health, and substance abuse services; prescription drugs; and support services like transportation, meals, and housing assistance. The current statute does not specify how funding should be distributed across these services. Some, including the Bush administration, seek a statutory set-aside requiring that a significant portion of the funding be used for “core medical services” as opposed to support services.³

Much of the reauthorization debate has focused on the Title I and II distribution formulas because they create inequalities in funding per AIDS case across cities and states and, most strikingly, because they create discrepancies in funding per AIDS case among states that bear similar AIDS burdens. In Title I, funds are distributed to eligible metropolitan areas (EMA) that have at least 2,000 estimated living AIDS cases. The formula for Title II funding distributes 80 percent of the state’s award based on the number of AIDS cases in its EMAs and 20 percent on cases outside of any EMAs. As a result, states that have no AIDS cases in their EMAs received on average \$3,592 per AIDS case, whereas states that have 75 percent or more of their cases in EMAs received on average \$4,955 per AIDS case.⁴ Statutory changes to current provisions that protect grantees from funding fluctuations or from disqualification when they no longer meet eligibility requirements (hold harmless and grandfathering) as well as double-counting of AIDS cases in EMAs will create funding winners and losers across cities and states. The Government Accountability Office testified to a Senate committee in June 2005 about these funding disparities and the funding shifts that would result from legislative changes.

KEY QUESTIONS

- What are the characteristics of the population of people living with HIV/AIDS in the United States? In what ways has the population changed most significantly over the past 25 years?
- How is HIV/AIDS treated and how has treatment changed since the beginning of the epidemic? What kinds of services and activities does Ryan White pay for?

- How is Ryan White funding currently distributed in Titles I and II? How have previous reauthorizations changed the distribution? How have hold harmless, grandfathering, and double-counting provisions affected the distribution of funds across EMAs and states? What are the consequences of these efforts to mediate dislocations in funding?
- What is the potential impact of leaving intact the current statutory requirement that HIV data be used for funding distribution for Titles I and II in FY 2007? What level of HIV cases would merit funding as an EMA?
- Should the funding formulas be modified to take into account severity of need by including factors beyond disease burden like poverty level, resource availability, and the cost of providing care? If so, what data are available to do so?
- How do Ryan White dollars fit into the broader public financing for HIV/AIDS treatment? Are there significant differences in access to care and the type of care available in different cities and states across the country? To what extent do these differences relate to Ryan White funding? How much variation is acceptable, considering differences in state Medicaid programs and local safety nets?
- Should the CARE Act play a more direct role in facilitating early diagnosis and prevention of HIV/AIDS? What are the projected costs to public programs (Medicaid, Medicare, Ryan White) absent improved preventive efforts?

SPEAKERS

Marcia Crosse, PhD, is a director in the Health Care Group in the Government Accountability Office (GAO). She has been responsible for overseeing multiple projects in the areas of biomedical research, bioterrorism, disease surveillance, HIV/AIDS, medical product safety, organ transplantation, and pharmaceutical regulation. Dr. Crosse began her GAO career in the Program Evaluation and Methodology Division in 1985 and joined the Health Care Group in 1996. She also has responsibility for leading GAO's work on military health care issues, including reviews of the TRICARE system.

Martin Shapiro, MD, PhD, MPH, is professor of medicine and professor of health services at the University of California, Los Angeles, where he joined the faculty in 1980. Dr. Shapiro was a member of the Institute of Medicine's Committee on Public Financing and Delivery of HIV Care. He was a principal investigator on the HIV Costs and Services Utilization Study (HCSUS), the only nationally representative study of AIDS care costs and AIDS patients' access to and quality of care.

David Holtgrave, PhD, has been professor and chair of the Department of Health, Behavior and Society at the Johns Hopkins Bloomberg School of Public Health since August 2005. He was professor of behavioral sciences and health education and professor of health policy and management in the Rollins School of Public Health at Emory University from 2001 through 2005. Prior to his tenure at Emory, Dr. Holtgrave served as the director of the Division of HIV/AIDS Prevention: Intervention Research and Support in the National Center for HIV, STD and TB Prevention at the Centers for Disease Control and Prevention in Atlanta, Georgia, for four years. He was a member of the Institute of Medicine's Committee on Public Financing and Delivery of HIV Care.

ENDNOTES

1. Kaiser Family Foundation (KFF), "The HIV/AIDS Epidemic in the United States," HIV/AIDS Policy Fact Sheet, November 2005; available at www.kff.org/hivaids/upload/3029-06.pdf.
2. HIV/AIDS Bureau (HAB), "The AIDS Epidemic and the Ryan White CARE Act. Past Successes + Future Challenges. 2004-2005," Health Resources and Services Administration (HRSA), available at <http://hab.hrsa.gov/publications/progress05>; and KFF, "Medicaid and HIV/AIDS," HIV/AIDS Policy Fact Sheet, September 2005, available at www.kff.org/hivaids/upload/7172-02.pdf.
3. Department of Health and Human Services, "Ryan White CARE Act Reauthorization Principles," fact sheet, July 27, 2005; available at www.dhhs.gov/news/press/2005pres/ryanwhite.html.
4. Marcia Crosse, Government Accountability Office, "Ryan White CARE Act: Factors that Impact HIV and AIDS Funding and Client Coverage," GAO-05-841T, testimony before the Subcommittee on Federal Financial Management, Government Information, and International Security, Committee on Homeland Security and Governmental Affairs, U.S. Senate, June 23, 2005; available at www.gao.gov/new.items/d05841t.pdf.



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