

**CAEAR Coalition**  
**September 2010 Membership Meeting**  
**Public Policy Documents**

- **CAEAR Coalition Business Meeting Agenda**
- **Appropriations Chart**
- **FY 2011 appropriations request letter to Congressional appropriators**
- **National HIV/AIDS Strategy Executive Summary**
- **FY2011 Senate Appropriations Report Language on Ryan White Program and Health Care Reform Implementation**
- **Panelist Questions from Town Hall Meeting**
- **Advocate's Roadmap on Health Care Reform and HIV/AIDS Care**
- **Health Care Reform Law – Advisory Panels, Boards and Commissions**

<b>Monday, September 20 - Business Meeting Day 1</b>	
<i>Time</i>	<i>Item</i>
8:30 am – 9:00 am	Registration
9:00 am – 9:30 am	Convene Meeting: Welcome, Introductions, and Agenda Review
9:30 am – 11:00 am	Update on Implementation of National HIV/AIDS Strategy ▪ <i>Jeff Crowley, Director of the Office of National AIDS Policy</i>
11:00 am – 11:15 am	Break
11:15 am – 12:30 pm	Strategic Planning Discussion ▪ <i>Update on Board discussion and next steps</i>
12:30 pm – 1:45 pm	Lunch (on your own)
1:45 pm – 3:30 pm	Update from Capitol Hill: Next Steps on FY 2011 Appropriations and Health Care Reform Implementation ▪ <i>Jon Bouker, Partner, Arent Fox</i>
3:30pm – 5:00 pm	Hill Visit Messages and Preparation

<b>Tuesday, September 21 - Business Meeting Day 2 and Advocacy Day</b>	
9:00 am – 10:30 am	Test, Link to Care, Plus Treat (TLC-Plus): A Local Perspective on Implementation ▪ <i>Angela Fulwood Wood, Deputy Director, Family and Medical Counseling Services, Washington, DC</i> ▪ <i>Tiffany West-Ojo, Bureau Chief of Strategic Information, HIV/AIDS, Hepatitis, STD and TB Administration, DC Department of Health</i>
10:30 am – 11:30 am	Follow-up and Next Steps on Health Care Reform Implementation and National HIV/AIDS Strategy Implementation
11:30 am – 5:00 pm	Lunch (on your own) and Capitol Hill Visits
<b>Wednesday, September 22 - Advocacy Day</b>	
8:00 am – 5:00 pm	Capitol Hill Visits



## Ryan White Program Appropriations: FY2011 Request

Program	CAEAR Coalition FY 2010 Request	President's FY 2010 Budget Request	FY 2010 Conference Report	CAEAR Coalition FY 2011 Request	President's FY 2011 Budget Request	House Approp. Subcom. FY 2011 Bill	Senate Approp. Full Com. FY 2011 Mark-up
Part A	\$766.1m (+\$103m)	\$671.1m (+\$8m)	\$679.1m (+\$16m)	\$905m (+225.9m)	\$679.1m (+\$0m)	\$694.0m (+\$15m)	\$679.1m (+\$0)
Part B Base	\$514.2m (+\$105.4m)	\$418.8m (+\$10m)	\$418.8m (+\$10m)	\$474.7m (+55.9m)	\$428.8m (+\$10m)	\$428.8 (+\$10m)	\$418.8m (+\$0)
Part B ADAP	\$1,083.6m (+\$268.6m)	\$835.0m (+\$20m)	\$835.0m (+\$20m)	\$1205.1m (+370.1m)	\$855.0m (+\$20m)	\$885.0m (+\$50m)	\$885.0m (+\$50m)
Part C	\$268.3m (+\$66.4m)	\$211.9m (+\$10m)	\$206.8m (+\$4.9m)	\$337.8m (+131m)	\$211.9m (+\$5.1m)	\$211.9m (+\$5m)	\$206.4m (-\$0.5m)*
Part D	\$134.6m (+\$57.8m)	+\$76.8m (+0)	\$77.8m (+\$0.9m)	\$84.8m (+7m)	\$77.8m (+\$0)	\$77.8m (+\$0)	\$77.8m (+\$0m)
Part F AETC	\$50.0m (+\$15.6m)	\$38.4m (+\$4m)	\$34.8m (+\$0.4m)	\$50m (+15.2m)	\$37.4m (+\$2.6m)	\$37.4m (+\$2.6)	\$34.7m (+0)
Part F Dental Reimb.	\$19.0m (+\$5.6M)	\$15.4m (+\$2m)	\$13.6m (+0.2m)	\$19m (+5.4m)	\$15.4m (+1.8m)	\$15.4m (+\$1.8m)	\$13.6m (+\$0)

\*Committee indicates that it has maintained funding at FY2010 levels. We are working to clarify the discrepancy.

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March 16, 2010

The Honorable Tom Harkin  
Chairman  
Subcommittee on Labor-HHS-Education  
Senate Appropriations Committee  
131 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable David R. Obey  
Chairman  
Subcommittee on Labor-HHS-Education  
House Appropriations Committee  
2358-B Rayburn House Office Building  
Washington, DC 20515

The Honorable Thad Cochran  
Ranking Member  
Subcommittee on Labor-HHS-Education  
Senate Appropriations Committee  
113 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Todd Tiahrt  
Ranking Member  
Subcommittee on Labor-HHS-Education  
House Appropriations Committee  
1016 Longworth House Office Building  
Washington, DC 20515

Dear Chairmen Harkin and Obey and Ranking Members Cochran and Tiahrt:

On behalf of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, I am writing to urge your support for increased funding for the Ryan White Program in the FY 2011 appropriations.

CAEAR Coalition is a national membership organization which advocates for federal appropriations, legislation, policy and regulations to meet the care, treatment, support service and prevention needs of people living with HIV/AIDS and the organizations that serve them. CAEAR Coalition's proactive national leadership is focused on the Ryan White Program as a central part of the nation's response to HIV/AIDS. CAEAR Coalition's members include Ryan White Program Part A, Part B, Part C and Part F consumers, grantees, and providers.

The reauthorization of the Ryan White Program signed in October 2009 was a tremendous victory for people living with HIV/AIDS and those who care for them. We are grateful for Congressional efforts to ensure that this vital program continued uninterrupted when it expired in September.

CAEAR Coalition respectfully requests that Congress provide the following FY 2011 funding for the Ryan White Program:

- **\$905m for Part A (+225.9m)**
- **\$474.7m for Part B base (+55.9m)**
- **\$1,205.1m for Part B ADAP (+370.1m)**
- **\$337.8m for Part C (+131m)**
- **\$84.8m for Part D (+7m)**
- **\$50m for Part F AETC (+15.2m)**
- **19m for Part F Dental (+5.4m)**

As President Obama noted when he signed the legislation in October, “over the past 19 years this legislation has evolved from an emergency response into a comprehensive national program for the care and support of Americans living with HIV/AIDS. It helps communities that are most severely affected by this epidemic and often least served by our health care system, including minority communities, the LGBT community, rural communities, and the homeless. It's often the only option for the uninsured and the underinsured. And it provides life-saving medical services to more than half a million Americans every year, in every corner of the country.”

The legislation passed last year includes small increases in the annual authorized appropriations for the program and, if appropriated, these increases would provide important and much-needed new funds to those on the ground. These authorized amounts, however, are well below the level of need in hard-hit communities, especially in light of years of stagnant funding. Attached are calculations highlighting the level of funding required in FY 2011 to bring Part A and Part C up to their required levels of funding by FY 2012 (see attachment A). It is also crucial that additional funds be made available to the AIDS Education and Training Centers in Part F to support the training of health care providers to care for the growing patient caseloads.

The Ryan White program's contributions to the nation's fight against HIV/AIDS are evident in our firsthand experiences with the program and confirmed by OMB's Program Assessment Rating Tool (PART). The PART found that the Ryan White Program has contributed to the decline in the number of new AIDS cases and deaths due to HIV/AIDS (see Attachment B). The PART assessment also gave the program a score of 100% in Program Results and Accountability, making it one of only seven out of 1,016 federal programs to receive that score. Key to its effectiveness is the program's proven ability to address disparities in access to HIV treatment and care—the program serves women and racial and ethnic minorities in significantly higher proportions than their representation among reported AIDS cases.

The FY 2011 appropriation presents a crucial initial opportunity for you to restore the Ryan White Program to the levels of funding demanded by the epidemic as the Centers for Disease Control and Prevention continue their increased efforts to expand HIV testing to help people living HIV learn their status. With the continued influx of newly diagnosed individuals into care and the additional 56,000 estimated new cases of HIV every year, the Ryan White program must receive adequate increases to meet the health care and supportive services needs of individuals already in care and those newly identified HIV patients.

The attached charts shows the ever-growing gap between the number of people living with AIDS in the U.S. in need of care and the resources available to serve them (see Attachment C). For example, between 2001 and 2007 the number of people living with AIDS grew 33% and yet funding for medical care and support services in the nation's hardest hit communities grew less than 12% between 2001 and 2010. Similarly, funding for Part C-funded, community-based primary care clinics, which provided medical care for people living with HIV/AIDS in rural and urban communities nationwide, grew by only 11% between 2001 and 2010 as the number of people they care for grew by 52%. We have also included additional background information on HIV/AIDS in the U.S. and on the Ryan White Program (see Attachments D and E).

CAEAR Coalition  
March 16, 2010

CAEAR Coalition looks forward to working with you and your committees to provide high quality, appropriate community-based HIV medical care, support services and treatment for the more than one million Americans living with HIV/AIDS.

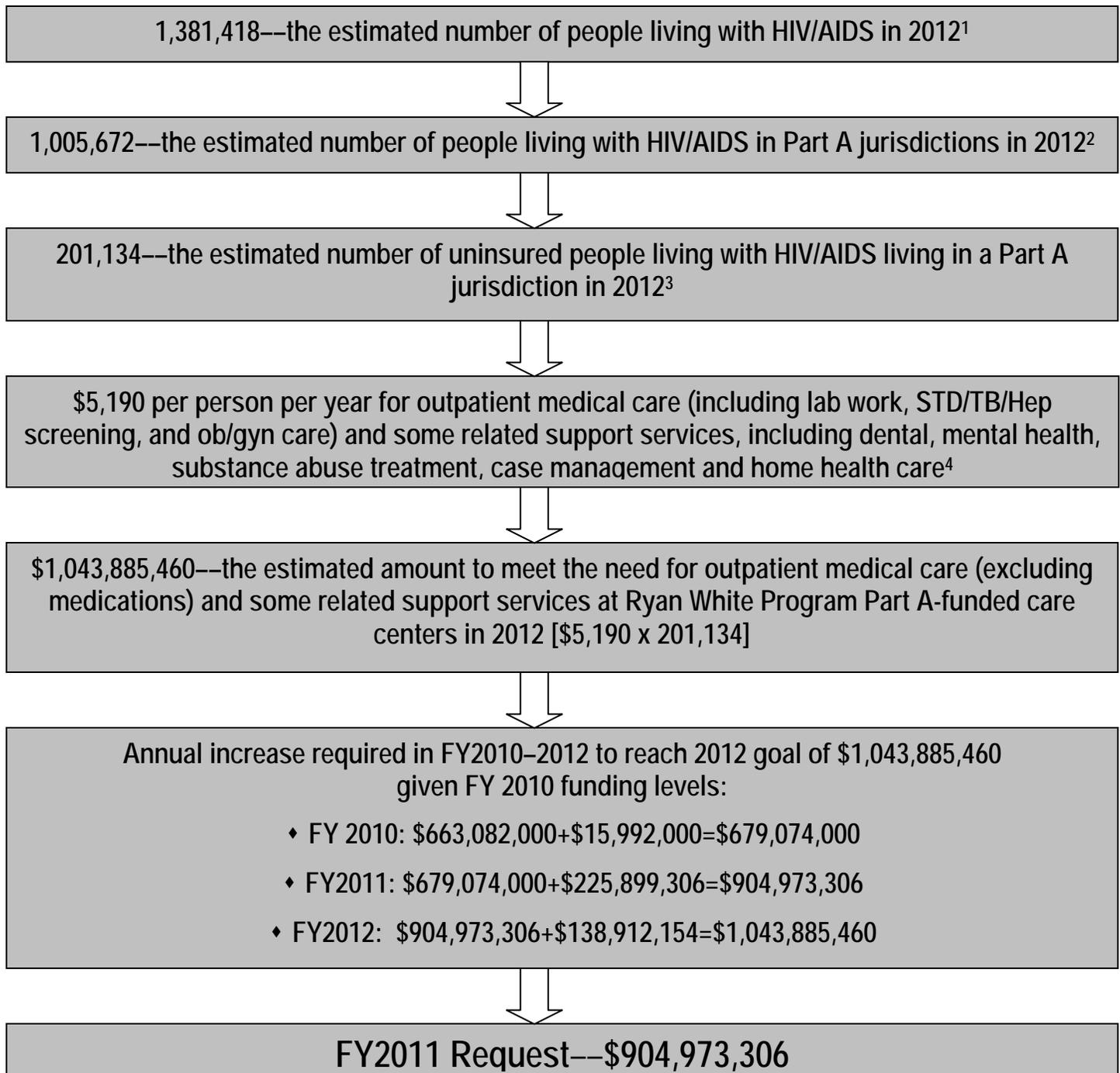
Sincerely,

A handwritten signature in black ink, appearing to read "Ernest Hopkins". The signature is fluid and cursive, with the first name "Ernest" written in a larger, more prominent script than the last name "Hopkins".

Ernest Hopkins  
Chair, Board of Directors

Attachments

## Building the Capacity of Ryan White Program Part A Services: FY 2010-2012



1. Based on the Centers for Disease Control and Prevention, New Estimates of U.S. HIV Prevalence, 2006. Estimate equals CDC's 2006 estimated cases multiplied by their annual estimated prevalence increase for the years 2007–2010.
2. Percentage based on *US Department of Health and Human Services Fiscal Year 2009 Justification of Estimates for Appropriations Committees*, p. 171.
3. Percentage based on data from Kaiser Family Foundation, Financing HIV/AIDS Care: A Quilt of Many Holes, May 2004.
4. Institute of Medicine, Committee on the Public Financing and Delivery of HIV Care, Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White, 2005. Cost estimates are based on data from a variety of studies from 1998 to 2002 and are not adjusted for medical inflation.

# Building the Capacity of Ryan White Program Part C Services: FY 2010–2012

1,381,418—estimated number of people living with HIV/AIDS in 2012<sup>1</sup>

248,070—estimated number of people living with HIV/AIDS served by Part C providers in 2008 [Number served in 2007 (236,032) + 5.1% annual increase<sup>2</sup>]

79,382—estimated number of uninsured living with HIV/AIDS served by Part C in 2008<sup>3</sup>

168,688—estimated number underinsured living with HIV/AIDS served by Part C providers in 2008<sup>3</sup>

\$3,501 per person per year for outpatient medical care (including lab work, STD/TB/Hep screening, and ob/gyn care) and some related support services, including dental, mental health, substance abuse treatment, case management<sup>4</sup>

\$277,916,382—estimated cost of providing care to uninsured people living with HIV [79,382x\$3,501]

\$129,383,696—est. cost of providing care to underinsured people living with HIV [168,688x\$767<sup>5</sup>]

\$407,300,078—estimated funding needed to meet demand for outpatient medical care (excluding medications) at Ryan White Program Part C care centers in 2012.<sup>5</sup>

Annual increases required in FY2010–2012 to reach 2012 goal of \$407,300,078, given FY 2010 funding levels:

- ♦ FY 2010: \$201,877,000+\$4,948,000=\$206,825,000
- ♦ FY2011: \$206,825,000+\$130,959,718=\$337,784,718
- ♦ FY2012: \$337,784,718+\$69,515,360=\$407,300,078

**FY2011 Request—\$337,784,718**

1. Based on the Centers for Disease Control and Prevention, New Estimates of U.S. HIV Prevalence, 2006. Estimate equals CDC's 2006 estimated cases multiplied by their annual estimated prevalence increase for the years 2007–2012.
2. 2007 data provided by the HRSA HIV/AIDS Bureau. Annual increase based on increase in patients served between 2006 and 2007.
3. Percentages of uninsured and underinsured from correspondence from Julie Gerberding, MD, MPH and Elizabeth Duke, PhD to The Honorable Henry Waxman regarding his questions on the 2006 Revised Recommendations for HIV testing and the impact on demand for services. September 9, 2008 (page 6). Available online at: <http://oversight.house.gov/story.asp?ID=1675>.
4. Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. *AIDS Care*. 2008;20:1050–6. The mean cost of care in the study is \$2,956 for the years 2002 and 2003. Adjusting that amount for medical inflation rates published online at [www.blus.gov/news.release/cpi.nr0.htm](http://www.blus.gov/news.release/cpi.nr0.htm) for the years 2004–2007 generates the estimated cost of \$3,501.
5. Conservative estimate of costs for underinsured. Based on Institute of Medicine, Committee on the Public Financing and Delivery of HIV Care, Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White, 2005, for average use of two often uncovered services: mental health services and substance abuse treatment.

## OMB: The Ryan White HIV/AIDS Program Works

*The White House Office of Management and Budget's assessment of the Ryan White Program found it to be in the **top 1% of all federal programs** in the area of "Program Results and Accountability."*

In its 2007 Program Assessment Rating Tool (PART), OMB gave the Ryan White Program its highest possible rating of "effective"—a distinction shared by only 18% of all programs rated. According to OMB, effective programs "set ambitious goals, achieve results, are well-managed and improve efficiency."

Ryan White Program PART Assessment Scores	
Purpose & Design	100%
Strategic Planning	86%
Program Management	91%
Program Results/Accountability	100%

Half of the OMB ranking is based on the category of "program results and accountability." Out of the 1,016 federal programs rated—98 percent of all federal programs—the **Ryan White Program was one of seven** that received a score of 100% in "Program Results and Accountability."

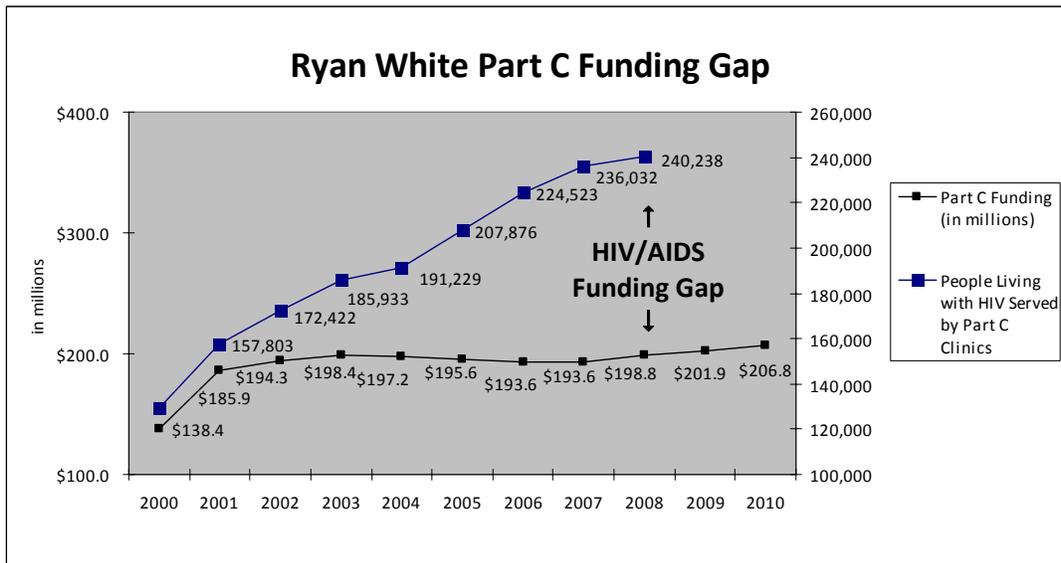
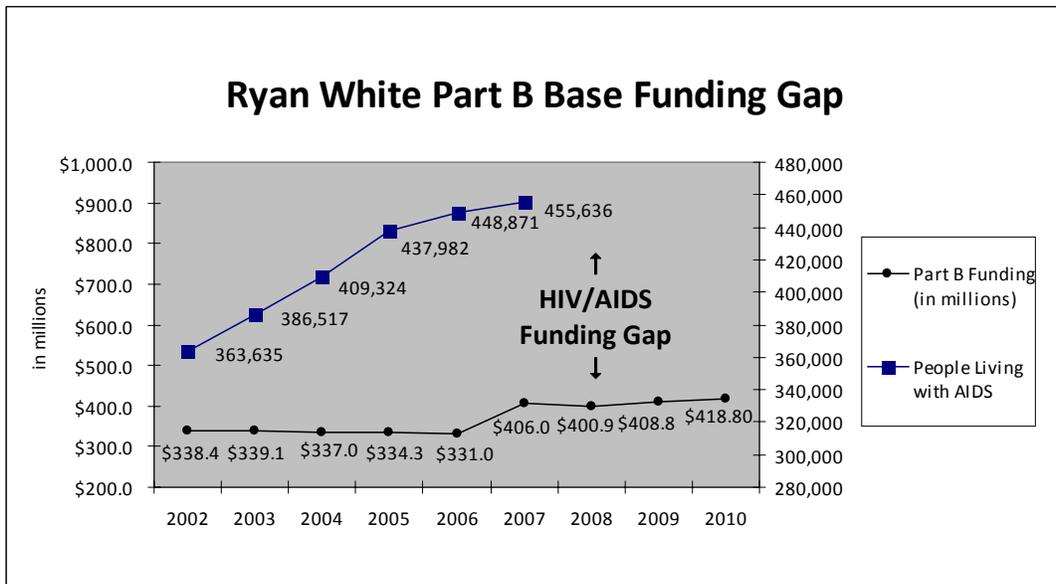
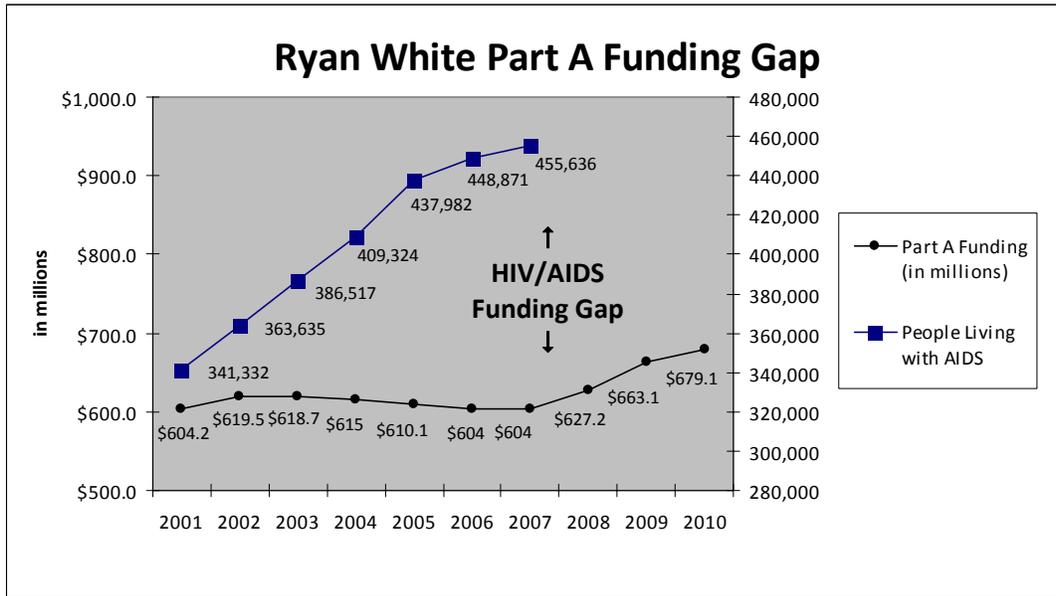
### OMB's Summary Assessment of the Ryan White Program

◆ **The program has had a positive impact. It has contributed to the decline in the number of AIDS cases and deaths due to HIV/AIDS.** From 1999 to 2003 deaths due to HIV/AIDS went from 5.3 to 4.7 per 100,000. A cause of the decrease is increased use of antiretroviral medications. In 2000 the program's AIDS Drug Assistance Program (ADAP) served 128,078 clients. In 2005 ADAP served 143,339 clients.

◆ **The program has exhibited strong and effective collaborations with similar programs.** The program collaborates with Federal, State and local partners, as well as with private and non-profit HIV/AIDS care, treatment and advocacy groups. By working with this wide range of partners, persons infected with and affected by HIV/AIDS receive coordinated comprehensive care and support services.

◆ **The program has demonstrated improved management and oversight of the use of Federal funds.** The previous PART review and other assessments indicated deficiencies in the oversight of grantees' use of Ryan White funds. The program has taken corrective action by expanding grantee technical assistance and monitoring grantee financial accountability and performance.

# HIV/AIDS Funding Gaps: FY 2001–2010



# HIV/AIDS Epidemic Remains a Public Health Emergency in the U.S.

## ➤ More People than Ever are Living with HIV and AIDS

- More than 1.1 million Americans living with HIV and AIDS.<sup>1</sup>
- 455,636 people living with AIDS in the 50 states, DC and dependent areas.<sup>2</sup>

## ➤ Almost Half of All People with HIV Who Need Anti-HIV Therapies Are Not Receiving Them

- 45% of HIV-infected people in the U.S. for whom antiretroviral therapy would likely be recommended are not receiving it.<sup>3</sup>

## ➤ HIV/AIDS in the U.S. Increasingly Affects Communities of Color, as Well as Economically-Depressed and Other Underserved Communities

- African Americans account for 50% of new AIDS diagnoses and Latinos account for 19% of new diagnoses, though they account for approximately 12% and 15% of the U.S. population, respectively.<sup>4</sup>
- Latina and African American women account for 77% of new infections among females in the U.S.<sup>5,6</sup> The rate of AIDS diagnoses for black women was nearly 23 times the rate for white women. The rate of AIDS diagnoses for black men was eight times the rate for white men.<sup>7</sup>

## ➤ Men who Have Sex with Men (MSM), Especially MSM of Color, Still Bear Large Brunt of Epidemic

- MSM made up more than two thirds (68%) of all men living with HIV in 2005, even though only about 5% to 7% of men in the United States reported having sex with other men.<sup>8</sup>
- A 2005 study of five large U.S. cities found that HIV prevalence among African American MSM was 46% and of those men, 68% were unaware of their HIV infection.<sup>9</sup>

## ➤ CDC Initiative Aims to Bring Thousands of New HIV+ Patients into Care

CDC's "Advancing HIV Prevention" initiative aims "to open up the door to [HIV] testing so that people can learn their status and get the appropriate treatment and prevention services that they deserve and need." Many of the estimated 200,000 people living with HIV in the U.S. who are unaware of their HIV status that are diagnosed under the new CDC initiative will turn to health care providers funded through the Ryan White Program for their HIV-related care.

## ➤ Public Programs are Key to Health Care Access

20% of the people living with HIV who receive HIV-related care are uninsured and 68% to 83% either rely on public-sector insurance programs or are uninsured.<sup>10</sup>

<sup>1</sup> Kaiser Family Foundation, The HIV/AIDS Epidemic in the United States; October 2008.

<sup>2</sup> CDC, HIV/AIDS Surveillance Report, Vol. 18, Cases of HIV Infection and AIDS in the United States and Dependent Areas, 2006

<sup>3</sup> Teshale EH, et al., "Estimated Number of HIV-infected Persons Eligible for and Receiving HIV Antiretroviral Therapy, 2003—United States," *12th Conference on Retroviruses and Opportunistic Infections*, Abstract #167; 2005.

<sup>4</sup> Kaiser Family Foundation, The HIV/AIDS Epidemic in the United States; October 2008.

<sup>5</sup> Kaiser Family Foundation, Black Americans and HIV/AIDS; October 2008.

<sup>6</sup> Kaiser Family Foundation, Latinos and HIV/AIDS; October 2008.

<sup>7</sup> CDC, HIV/AIDS Among African Americans; August 2008.

<sup>8</sup> CDC, HIV/AIDS and Men Who Have Sex with Men; <http://www.cdc.gov/hiv/topics/msm/index.htm>, June 28, 2007

<sup>9</sup> CDC, *Morbidity and Mortality Weekly Report*, HIV Prevalence, Unrecognized Infection, and HIV Testing Among Men Who Have Sex with Men --- Five U.S. Cities, June 2004--April 2005, 54(24);597-601.

<sup>10</sup> Kaiser Family Foundation, Financing HIV/AIDS Care, A Quilt with Many Holes; May 2004.

# The Ryan White HIV/AIDS Program: Key to America's Response to the Domestic HIV/AIDS Crisis

## ➤ Services from Coast to Coast in Communities Large and Small

The Ryan White Program provides lifesaving medical care and support services to more than half a million low-income people living with HIV/AIDS each year. Services are provided in urban and rural communities in all 50 states and the territories. The program is a model for the efficient delivery of services that respond to local needs and reduce the use of more costly emergency services and inpatient facilities. Key to that success has been the flexibility the Ryan White Program provides to states and localities to tailor program services to fill gaps in their networks of care.

## ➤ Multi-Part Structure Directs Services Where They Are Most Needed

The Ryan White Program's multi-part structure was designed to efficiently distribute resources where they are needed most. Part A directs funds to the hardest-hit municipalities, while Part C has been used to improve access to care in rural and urban communities in great need. Part D provides access to specialized care for women, children and families, while Part F supports oral health care and specialized training for health care providers through the AIDS Education and Training Centers. The Minority AIDS Initiative provides resources across the program to enhance access for racial and ethnic minorities.

## ➤ Adapting to Evolving Treatment Options

The Ryan White Program has evolved along with the HIV epidemic. Originally a source of care for those at the end of life, it now supports the comprehensive medical care and enhancing support services necessary for the complex treatment of HIV/AIDS with highly active antiretroviral therapy (HAART). Care and treatment offered through Ryan White-funded providers and the Part B AIDS Drug Assistance Programs help people living with HIV/AIDS determine and access the most appropriate drug regimens.

One in four people living with HIV in the U.S. receives their HIV medications through Ryan White Program-funded AIDS Drug Assistance Programs (ADAP).

*Source: U.S. Department of Health and Human Services, Fiscal Year 2009, Justification of Estimates for Appropriations Committees, Health Resources and Services Administration.*

## ➤ Medical Care and Support Services Make Treatment with Anti-HIV Medications Possible

The administration of drugs does not by itself result in successful treatment; additional medical and support services are also essential. To that end, the Ryan White program provides a medical care and other services to support the management of and adherence to complex drug regimens. The

selection and initiation of an antiretroviral regimen are critical elements of successful HIV treatment. The programs supported by the Ryan White Program provide the infrastructure in which people living with HIV/AIDS can take an anti-HIV/AIDS drug regimen under proper ongoing medical supervision, including costly

By 2006, 88.6% of Ryan White Program-funded primary medical care providers had implemented a quality management program.

*Source: U.S. Department of Health and Human Services, Fiscal Year 2009, Justification of Estimates for Appropriations Committees, Health Resources and Services Administration.*

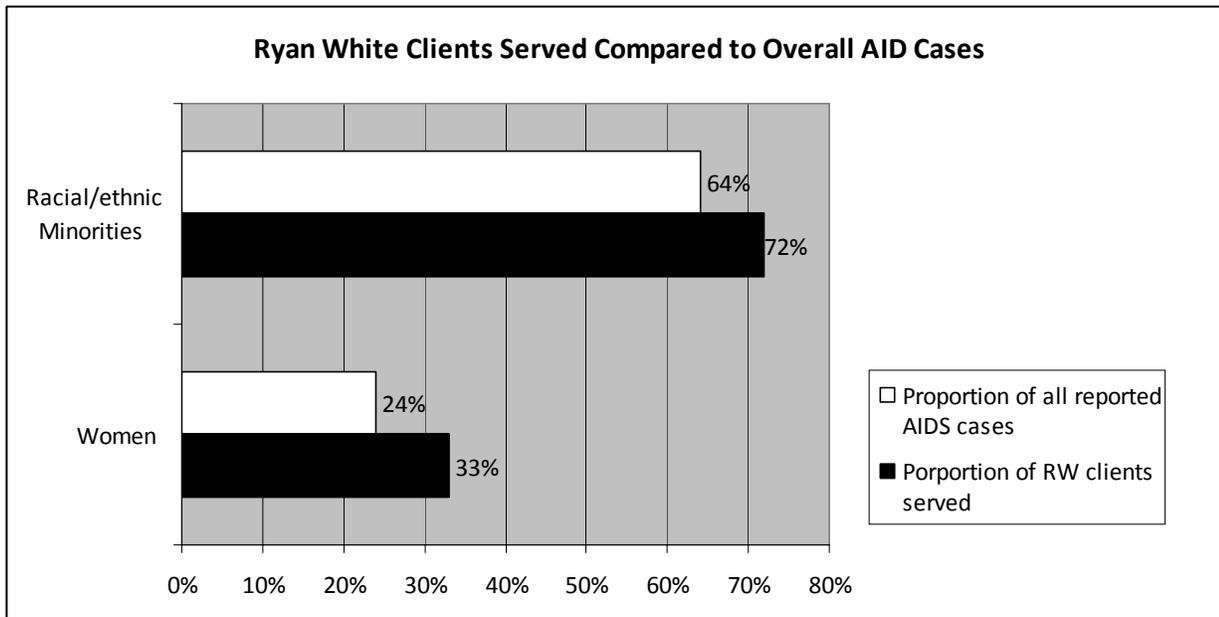
Attachment E

laboratory testing. Without the experience and expertise of these medical professionals—many of them trained through the Ryan White Program—the powerful drugs used to manage HIV/AIDS could easily be misused or insufficiently managed and result in serious consequences such as viral resistance, complications, including increased risk of heart disease, high cholesterol, anemia, diabetes, kidney and pancreatic and liver dysfunction; and treatment failure.

Competing needs, such as food, nutrition services, and housing, and barriers to care, such as lack of transportation or childcare, limit access to HIV health care services. One study found that more than one-third of people living with HIV in the health care system postponed or went without care during a six-month period because of competing needs and barriers. These barriers were also associated with significantly greater odds for never receiving antiretroviral treatment. Others went without food, housing, and clothes in order to pay for their care.<sup>1</sup> While the majority of Ryan Program funds support HIV treatment, a portion also provide key support services, such as food and transportation, as well as case management services to link people living with HIV/AIDS to medical care and support services.

➤ **Addressing Disparities in Access to Care**

The Ryan White Program provides HIV/AIDS care and treatment services to a significantly higher proportion of racial/ethnic minorities and women than their representation among reported AIDS cases.



Source: U.S. Department of Health and Human Services, Fiscal Year 2009, Justification of Estimates for Appropriations Committees, Health Resources and Services Administration.

**Footnote**

<sup>1</sup> Cunningham WE, Andersen RM, Katz MH, et al. The impact of competing subsistence needs and barriers on access to medical care for persons with human immunodeficiency virus receiving care in the United States. *Medical Care*. 1999;37(12):1270-1281.



# NATIONAL HIV/AIDS STRATEGY FOR THE UNITED STATES

JULY 2010





# Executive Summary

When one of our fellow citizens becomes infected with the human immunodeficiency virus (HIV) every nine-and-a-half minutes, the epidemic affects all Americans. It has been nearly thirty years since the first cases of HIV garnered the world's attention. Without treatment, the virus slowly debilitates a person's immune system until they succumb to illness. The epidemic has claimed the lives of nearly 600,000 Americans and affects many more.<sup>1</sup> Our Nation is at a crossroads. We have the knowledge and tools needed to slow the spread of HIV infection and improve the health of people living with HIV. Despite this potential, however, the public's sense of urgency associated with combating the epidemic appears to be declining. In 1995, 44 percent of the general public indicated that HIV/AIDS was the most urgent health problem facing the Nation, compared to only 6 percent in March 2009.<sup>2</sup> While HIV transmission rates have been reduced substantially over time and people with HIV are living longer and more productive lives, approximately 56,000 people become infected each year and more Americans are living with HIV than ever before.<sup>3,4</sup> Unless we take bold actions, we face a new era of rising infections, greater challenges in serving people living with HIV, and higher health care costs.<sup>5</sup>

President Obama committed to developing a *National HIV/AIDS Strategy* with three primary goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. To accomplish these goals, we must undertake a more coordinated national response to the HIV epidemic. The Strategy is intended to be a concise plan that will identify a set of priorities and strategic action steps tied to measurable outcomes. Accompanying the Strategy is a Federal Implementation Plan that outlines the specific steps to be taken by various Federal agencies to support the high-level priorities outlined in the Strategy. This is an ambitious plan that will challenge us to meet all of the goals that we set. The job, however, does not fall to the Federal Government alone, nor should it. Success will require the commitment of all parts of society, including State, tribal and local governments, businesses, faith communities, philanthropy, the scientific and medical communities, educational institutions, people living with HIV, and others. The vision for the *National HIV/AIDS Strategy* is simple:

*The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.*

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1. CDC. *HIV/AIDS Surveillance Report*. 2007; 19: 7. Available at <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf>

2. Kaiser Family Foundation. *2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic*. April 2009.

3. CDC. *Estimates of new HIV infections in the United States*. August 2008. Available at <http://www.kff.org/kaiserpolls/upload/7889.pdf>

4. CDC. *HIV Prevalence Estimates—United States*, 2006. *MMWR* 2008;57(39):1073-76.

5. If the HIV transmission rate remained constant at 5.0 persons infected each year per 100 people living with HIV, within a decade, the number of new infections would increase to more than 75,000 per year and the number of people living with HIV would grow to more than 1,500,000 (*JAIDS*, in press).

## Reducing New HIV Infections

More must be done to ensure that new prevention methods are identified and that prevention resources are more strategically concentrated in specific communities at high risk for HIV infection. Almost half of all Americans know someone living with HIV (43 percent in 2009).<sup>6</sup> Our national commitment to ending the HIV epidemic, however, cannot be tied only to our own perception of how closely HIV affects us personally. Just as we mobilize the country to support cancer prevention and research whether or not we believe that we are at high risk of cancer, or just as we support investments in public education whether or not we have children, success at fighting HIV calls on all Americans to help us sustain a long-term effort against HIV. While anyone can become infected with HIV, some Americans are at greater risk than others. This includes gay and bisexual men of all races and ethnicities, Black men and women, Latinos and Latinas, people struggling with addiction, including injection drug users, and people in geographic hot spots, including the United States South and Northeast, as well as Puerto Rico and the U.S. Virgin Islands. By focusing our efforts in communities where HIV is concentrated, we can have the biggest impact in lowering all communities' collective risk of acquiring HIV.

We must also move away from thinking that one approach to HIV prevention will work, whether it is condoms, pills, or information. Instead, we need to develop, evaluate, and implement effective prevention strategies and combinations of approaches including efforts such as expanded HIV testing (since people who know their status are less likely to transmit HIV), education and support to encourage people to reduce risky behaviors, the strategic use of medications and biomedical interventions (which have allowed us, for example, to nearly eliminate HIV transmission to newborns), the development of vaccines and microbicides, and the expansion of evidence-based mental health and substance abuse prevention and treatment programs. It is essential that all Americans have access to a shared base of factual information about HIV. The Strategy also provides an opportunity for working together to advance a public health approach to sexual health that includes HIV prevention as one component. To successfully reduce the number of new HIV infections, there must be a concerted effort by the public and private sectors, including government at all levels, individuals, and communities, to:

- Intensify HIV prevention efforts in communities where HIV is most heavily concentrated.
- Expand targeted efforts to prevent HIV infection using a combination of effective, evidence-based approaches.
- Educate all Americans about the threat of HIV and how to prevent it.

## Increasing Access to Care and Improving Health Outcomes for People Living with HIV

As a result of our ongoing investments in research and years of clinical experience, people living with HIV can enjoy long and healthy lives. To make this a reality for everyone, it is important to get people with HIV into care early after infection to protect their health and reduce their potential of transmitting the virus to others. For these reasons, it is important that all people living with HIV are well supported in a

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6. Kaiser Family Foundation. 2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic. April 2009. Available at <http://www.kff.org/kaiserpolls/upload/7889.pdf>

regular system of care. The *Affordable Care Act*, which will greatly expand access to insurance coverage for people living with HIV, will provide a platform for improvements in health care coverage and quality. High risk pools are available immediately. High risk pools will be established in every state to provide coverage to uninsured people with chronic conditions. In 2014, Medicaid will be expanded to all lower income individuals (below 133% of the Federal poverty level, or about \$15,000 for a single individual in 2010) under age 65. Uninsured people with incomes up to 400% of the Federal poverty level (about \$43,000 for a single individual in 2010) will have access to Federal tax credits and the opportunity to purchase private insurance coverage through competitive insurance exchanges. New consumer protections will better protect people with private insurance coverage by ending discrimination based on health status and pre-existing conditions. Gaps in essential care and services for people living with HIV will continue to need to be addressed along with the unique biological, psychological, and social effects of living with HIV. Therefore, the Ryan White HIV/AIDS Program and other Federal and State HIV-focused programs will continue to be necessary after the law is implemented. Additionally, improving health outcomes requires continued investments in research to develop safer, cheaper, and more effective treatments. Both public and private sector entities must take the following steps to improve service delivery for people living with HIV:

- Establish a seamless system to immediately link people to continuous and coordinated quality care when they are diagnosed with HIV.
- Take deliberate steps to increase the number and diversity of available providers of clinical care and related services for people living with HIV.
- Support people living with HIV with co-occurring health conditions and those who have challenges meeting their basic needs, such as housing.

### Reducing HIV-Related Health Disparities

The stigma associated with HIV remains extremely high and fear of discrimination causes some Americans to avoid learning their HIV status, disclosing their status, or accessing medical care.<sup>7</sup> Data indicate that HIV disproportionately affects the most vulnerable in our society—those Americans who have less access to prevention and treatment services and, as a result, often have poorer health outcomes. Further, in some heavily affected communities, HIV may not be viewed as a primary concern, such as in communities experiencing problems with crime, unemployment, lack of housing, and other pressing issues. Therefore, to successfully address HIV, we need more and better community-level approaches that integrate HIV prevention and care with more comprehensive responses to social service needs. Key steps for the public and private sector to take to reduce HIV-related health disparities are:

- Reduce HIV-related mortality in communities at high risk for HIV infection.
- Adopt community-level approaches to reduce HIV infection in high-risk communities.
- Reduce stigma and discrimination against people living with HIV.

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7. Mahajan AP, Sayles JN, Patel VA, et al. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS* 2008;22(Suppl 2):S67-S69.

## Achieving a More Coordinated National Response to the HIV Epidemic in the United States

The Nation can succeed at meeting the President's goals. It will require the Federal Government and State, tribal and local governments, however, to do some things differently. Foremost is the need for an unprecedented commitment to collaboration, efficiency, and innovation. We also must be prepared to adjust course as needed. This Strategy is intended to complement other related efforts across the Administration. For example, the *President's Emergency Plan for AIDS Relief (PEPFAR)* has taught us valuable lessons about fighting HIV and scaling up efforts around the world that can be applied to the domestic epidemic. The *President's National Drug Control Strategy* serves as a blueprint for reducing drug use and its consequences, and the *Federal Strategic Plan to Prevent and End Homelessness* focuses efforts to reduce homelessness and increase housing security. The White House Office of National AIDS Policy (ONAP) will work collaboratively with the Office of National Drug Control Policy and other White House offices, as well as relevant agencies to further the goals of the Strategy. The Strategy is intended to promote greater investment in HIV/AIDS, but this is not a budget document. Nonetheless, it will inform the Federal budget development process within the context of the fiscal goals that the President has articulated. The United States currently provides more than \$19 billion in annual funding for domestic HIV prevention, care, and research, and there are constraints on the magnitude of any potential new investments in the Federal budget. The Strategy should be used to refocus our existing efforts and deliver better results to the American people within current funding levels, as well as to highlight the need for additional investments. Our national progress will require sustaining broader public commitment to HIV, and this calls for more regular communications to ensure transparency about whether we are meeting national goals. Key steps are to:

- Increase the coordination of HIV programs across the Federal government and between federal agencies and state, territorial, tribal, and local governments.
- Develop improved mechanisms to monitor and report on progress toward achieving national goals.

This Strategy provides a basic framework for moving forward. With government at all levels doing its part, a committed private sector, and leadership from people living with HIV and affected communities, the United States can dramatically reduce HIV transmission and better support people living with HIV and their families.

**FY2011 Senate Appropriations Committee Report Language**

The committee is aware that many of the benefits currently provided through the Ryan White Care Act programs will become available to people living with HIV/AIDS over the next few years through State high-risk pools, health exchanges and other newly authorized programs. The Committee expects HRSA to offer a plan for how to transition Ryan White benefits into a larger system of care so that Ryan White resources may be targeted to the areas of most need. The plan should include a year-by-year list of actions needed by the administration, the Congress and the States in order to ensure the smoothest possible transition for beneficiaries. The Committee expects the plan no later than 8 months after enactment of this act.

# CAEAR Coalition Town Hall – Health Care Reform and Ryan White: What Must Be Done To Ensure They Fit

## Panelist Questions

1. How will the landscape of HIV care and treatment change for low-income and currently uninsured/underinsured people living with HIV as health care reform is implemented? In urban environments? In rural and suburban areas? How will we ensure that consumers of services have access to health care providers with HIV expertise as we seek to mainstream HIV care and de-stigmatize HIV status?
2. Can you explain what support will be provided to those who qualify for insurance exchanges, but cannot afford the premiums, deductibles and co-pays?
3. Do you think the advocacy organizations you represent are preparing your constituents for all that reform entails, including consumers having more choices, the ubiquity of electronic medical and billing records, the necessity to contract/negotiate service agreements with health insurance providers? What steps should all grantees and sub-grantees be taking now to prepare for the changes?
4. How can Part A and Part B grantees support their sub-grantees and help prepare for the changes ahead?
5. The Ryan White Program has supported the development of a model of care that has carried us through the worst days of the crisis. We have built systems of care in rural and urban environments that are serving uninsured and underinsured people living with HIV/AIDS. When the coverage expansion under health reform takes place in 2014, will the Ryan White program still be needed?
6. If we agree it will be important to maintain Ryan White funding -- what should we be doing to document and evaluate the continued role for Ryan White?
7. Once health care reform is fully implemented, what role will Ryan White play in providing services and who will it serve? What would you recommend as continued funding priorities under the Ryan White Program? What are the gaps in care going to be?
8. Currently the Ryan White Program plays an important role in covering the care for people with HIV at an acceptable compensation rate to most providers. This is in stark contrast to the current Medicaid reimbursement rates that are woefully below the actual cost of providing HIV care. Some of our best providers are refusing to accept more Medicaid clients at a time when many people living with HIV will be enrolling in Medicaid for their medical care. Will a mechanism be put in place in the new health care environment to cover the gap between Medicaid reimbursement rates and the actual cost of care that doesn't leave HIV medical providers with significant uncompensated costs? Is there a role for the Ryan White in addressing this problem?

9. Now that localities and states have largely established their systems of care through Ryan White, the eligible services are largely established by statute and the available resources are at a steady state, what is the role of the planning councils? What can these bodies do to prepare for the implementation of and transition to these new systems at the local level?
  
10. What are the key points that HRSA should make in the plan they must prepare for the Senate? How can we ensure that grantees, providers and consumers will be invited to participate in the process used to develop the plan?

# Securing Health Care for People with HIV and AIDS: An Advocate's Roadmap on Implementing Health Care Reform and Bridging Current and On-going Access to Care Gaps

The passage of health care reform in March of 2010 coupled with the announcement of a National HIV/AIDS Strategy (NHAS) in July 2010 signal important steps forward in the fight to secure health care for the most vulnerable populations. Provisions in the health care reform law – including expansion of Medicaid, increased funding for prevention, the creation of state-based health insurance exchanges, as well as the enactment of numerous regulatory checks on the insurance industry – will undoubtedly improve access to care for people living with HIV and AIDS. However, there are significant gaps and limitations in both health care reform and NHAS: many of the reforms that will most benefit people living with HIV and AIDS do not go into effect until 2014; the overall effectiveness of many important provisions in the reform law relies on successful federal agency rule-making and implementation over the next several years; and while NHAS provides an outline for some major steps toward increasing access to care, it is largely silent as to the expansion of care and treatment until key reform provisions go into effect in 2014. Ongoing advocacy efforts are needed to address these limitations and close these gaps.

In the coming years, advocacy will involve three targeted areas and phases: (1) ensuring that the promise of health care reform is fulfilled through active participation in the law's implementation; (2) using the NHAS and other advocacy efforts to secure a bridge to 2014 for people living HIV and AIDS; and (3) looking beyond health care reform to address the health care and essential support service needs that are left unmet even after health care reform and NHAS are fully implemented.



Prepared by  
Harvard Law School Health Law and Policy Clinic  
and Treatment Access Expansion Project

# Major Health Care Reform Provisions Affecting People with HIV and AIDS

## 2010

- Early expansion of Medicaid if states choose
- Temporary high risk pools for people with pre-existing conditions
- Prohibition against rescissions in all private health insurance plans
- Prohibition against lifetime benefit limits for all private health insurance plans
- Prohibition and/or restrictions on annual benefit limits in all private health insurance plans\*
- \$250 Rebates for Medicare Part D “doughnut hole”
- Required coverage of preventive care and immunizations without cost sharing for all private health insurance plans\*\*
- Increased funding for community health centers by \$11 billion over the next 5 years
- Creation of public health fund for prevention and public health programs, which allocates \$500 million in FY 2010, increasing annually up to \$2 billion in FY 2015 and thereafter

## 2011

- Medicaid Health Home program allows states to provide coordinated care through a health home for individuals with chronic conditions
- 50% discount on brand-name drugs for Medicare beneficiaries who enter the Medicare Part D coverage gap

## 2014

- Medicaid eliminates categorical eligibility and expands coverage to all those with income up to 133% of the federal poverty level (FPL) (in 2010, \$14,404 for an individual and \$29,327 for a family of four) with increased federal funding to pay for newly-eligible beneficiaries
- Qualified health plans offered through state exchanges as well as Medicaid benefits packages for newly-eligible beneficiaries must include “essential health benefits,” to be defined by the Secretary of Health and Human Services
- Prohibition on pre-existing condition exclusions for all private health insurance plans (starts in 2010 for children)\*
- Prohibition on discrimination based on health status for all private health insurance plans\*\*
- Premiums charged by health insurance issuer for new coverage offered in individual or small-group markets and exchanges may only vary by whether an individual or family is covered; the geographic rating area; age; and tobacco use\*
- Guaranteed availability of coverage from insurance carriers selling health plans in individual and group markets and exchanges\*\*
- Premium tax credits for individuals and families with income 133% to 400% FPL to purchase insurance through exchanges
- Cost-sharing subsidies for individuals and families with up to 250% FPL to purchase insurance through exchanges

\*Does not apply to grandfathered plans (defined broadly as a group health plan or group or individual health insurance coverage in which individuals were enrolled on March 23, 2010).<sup>1</sup>

\*\*Does not apply to grandfathered plans.

## **PHASE I: FULFILLING THE PROMISE OF HEALTH CARE REFORM BY MONITORING FEDERAL IMPLEMENTATION AND BUILDING STATE CAPACITY**

Many of the fine details as to the scope of the health care reform law are left to numerous federal agencies, particularly the Department of Health and Human Services. The HIV/AIDS community must continue to monitor implementation actions and comment as important regulations are proposed by the relevant federal agencies to ensure the community's needs are adequately addressed. The National HIV/AIDS Strategy (NHAS) complements many of the health care reform provisions, and advocates should ensure that the health care reform law is implemented in ways that forward the goals and implementation plan of the NHAS.

### **Essential Health Benefits Package**

The health care reform law requires a minimum “essential health benefits” package for those individuals that become newly eligible for Medicaid as well as for those insured through the private, state-level insurance exchanges starting in 2014.<sup>2</sup> The law sets out the basic requirements of the package – requiring coverage for ambulatory patient services, emergency services, hospitalization, maternity and newborn care, mental health and substance use disorder services, including behavioral health treatment, prescription drugs, rehabilitative and habilitative services and devices, laboratory services, preventive and wellness services and chronic disease management, pediatric services, including oral and vision care. However, implementation beyond this basic mandate is left to the discretion of the Secretary of Health and Human Services.

#### ➤ *Advocacy Targets:*

- *Federal: actively participate in the implementation process by submitting comments to the Secretary of Health and Human Service urging her to define the essential health benefits package in ways that provide the scope and level of services needed to meet the care and treatment needs of individuals living with HIV.<sup>3</sup>*
- *State: urge state officials to also weigh in with the Secretary and, engage and train state Medicaid offices and providers on the new benefits requirements once they are finalized.*

### **State Option to Provide Health Homes for Medicaid Enrollees with Chronic Conditions**

The Medicaid Home Health program allows states to amend their Medicaid programs to provide coordinated care through a health home for individuals with chronic conditions. Specifically, the Home Health Program gives individuals the opportunity to select a provider or health team to operate as a health home and allows patients access to more integrated and holistic provision of care. For the first two years a state plan amendment is in effect, states receive enhanced federal funding – a 90% Federal Medical Assistance Percentage (FMAP) – which helps to support better information sharing between health providers through investments in information technology, better coordination of care, and increased access to support services.<sup>4</sup> The law provides the following list of qualifying chronic conditions: a mental health condition; a substance use disorder; asthma; diabetes; heart disease; or being overweight, as evidenced by having a body mass index over 25.

➤ *Advocacy Targets:*

- *Federal: push HHS for inclusion of HIV and AIDS in regulations defining what qualifies as a “chronic condition” and ensure that states are provided with appropriate guidance as to how to set up these programs.*
- *State: encourage states to consider amending their state Medicaid plans to include this holistic coverage and thus become eligible for the 90% FMAP rates.*

### **Increased Funding for Community Health Centers**

The health care reform law includes billions of dollars in funding and grants for community health centers, including \$11 billion in funding for the operation, expansion and construction of health centers throughout the nation over the next five years.<sup>5</sup> For instance, the federal government recently announced the availability of \$250 million in grants for New Access Points to support more than 350 new Health Center service delivery sites in 2011.<sup>6</sup>

➤ *Advocacy Targets:*

- *Federal: push the Health Resources and Services Administration (HRSA) to encourage centers applying for New Access Point grants to include comprehensive health and support services for people living with HIV and AIDS.*
- *State: encourage health centers to apply for grants to expand services for people living with HIV and AIDS. Clinics that are not in compliance with federal rules regarding qualified health centers should consider bringing themselves into compliance to be eligible for federal grants.*

### **Inclusion of HIV/AIDS in the Prevention and Wellness Focus of Health Care Reform**

#### *Coverage of prevention services in private health insurance*

Beginning on September 23, 2010, all group and individual market health plans (except grandfathered plans) will be required to cover recommended preventive services without cost sharing.<sup>7</sup> On July 14, 2010, the Departments of Health and Human Services, Labor, and Treasury released a new regulation detailing the preventive services to be covered, including: HIV testing for all adolescents and adults at increased risk for HIV infection (risk factors defined by U.S. Preventive Services Task Force “Clinical Considerations”<sup>8</sup>); blood pressure, diabetes, and cholesterol tests; cancer screenings; counseling from a health care provider on smoking cessation, weight loss, nutrition, mental health, and alcohol use; routine vaccines; flu and pneumonia shots; counseling, screening, and vaccines for healthy pregnancies; and regular well-baby and well-child visits from birth to age twenty-one.<sup>9</sup>

➤ *Advocacy Targets:*

- *Federal: in keeping with CDC recommendations, seek coverage for more routine testing of adults and adolescents ages 13-64, rather than only those at increased risk for HIV.*

#### *Funding for HIV/AIDS prevention initiatives*

The health care reform law contains numerous prevention and wellness initiatives and offers important opportunities for advocates to promote HIV/AIDS and infectious disease prevention, including establishment of a \$500 million Prevention and Public Health Fund beginning in 2010 (increasing to \$2 billion in 2015 and

subsequent years).<sup>10</sup> Of this \$500 million, only \$30 million from the Prevention and Public Health Fund has thus far been earmarked to support HIV prevention efforts.<sup>11</sup>

➤ *Advocacy Targets:*

- *Federal: ensure that the Department of Health and Human Services (HHS) targets funds to support a broad range of HIV prevention and public health services need, including grants for community-based organizations, funding for studies and initiatives addressing stigma, and funding to shore up state HIV/AIDS budgets.*
- *State: ensure that health centers and state health officials are aware of federal funding opportunities and continually check the HRSA website for new community-based grants funded through the prevention and public health fund.*

*Primary Care Workforce Training and Expansion*

The Department of Health and Human Services (HHS) has set aside \$250 million from the Prevention and Public Health Fund in 2010 alone for investing in the development of an expanded primary care workforce, with a focus on underserved and particularly vulnerable populations.<sup>12</sup> This funding will be used for: creating additional primary care residency slots; supporting physician assistant training in primary care; encouraging students to pursue full-time nursing careers; establishing new nurse practitioner-led clinics; and encouraging states to plan for and address health professional workforce needs.

➤ *Advocacy Targets:*

- *Federal: push HHS to secure funding for training and retention of HIV/AIDS specialists as well as primary care physicians; work with HRSA to use the AIDS Education and Training Centers funded under Part F of Ryan White Programs as a model for broader health workforce training, especially around treatment for chronic conditions.*
- *State: work with states to encourage health professional workforce development, for instance by developing and collaborating with community health worker networks, and ensure that state health officials, health centers, and community-based organizations are aware of new federal funding opportunities.*

**Temporary High Risk Pools**

To provide immediate access to care before 2014, the health care reform law allocates \$5 billion for the creation of temporary high risk pools in every state and the District of Columbia, allowing immediate access to coverage for people living with HIV who have been excluded from the private insurance market based on a pre-existing condition.<sup>13</sup> Advocates were unsuccessful in getting HIV and AIDS included on a federal list of automatically qualifying pre-existing conditions; however, most state pools elected on their own to include HIV and AIDS as such automatically qualifying conditions. A significant hurdle to access to the coverage provided by these pools is cost. Premiums vary based on age and whether the applicant is a smoker – in Pennsylvania, for instance, the average monthly premium will be \$283 a month with a \$1,000 deductible.<sup>14</sup> Excluding premiums, annual out-of-pocket costs in the new plans will be limited, with a \$5,940 maximum for co-pays and deductibles.<sup>15</sup>

➤ *Advocacy Targets:*

- *Federal: push HRSA to explicitly allow Ryan White Program funds to be used to wrap-around risk pool coverage to address unmet care and service needs and to allow use of ADAP funds to cover the premiums, copayments and deductibles of high risk pool insurance.*
- *State: push states that have opted to run their own plan to stream-line the application process, for instance by allowing HIV as an automatic eligibility criterion and to use Ryan White funds for both wrap-around coverage and to meet beneficiary payment obligations.*

## **Integration of Ryan White Programs into Health Care Reform Initiatives**

Ryan White programs offer an important blueprint for the expansion of comprehensive health and support services for people with chronic illnesses. In many ways, Ryan White programs serve as a best-practices model for comprehensive and holistic provision of care and treatment. As major health care reform provisions go into effect, however, the role of Ryan White will undoubtedly change. Advocacy around integration of Ryan White providers into Medicaid and state exchange provider networks, for instance, will be crucial to ensure seamless access to care for the thousands of people newly-eligible for Medicaid and private insurance coverage. Integration of Ryan White programs and models of care into Medicaid and private insurance models is also important to ensure a smooth health care reform transition for those currently receiving care.

➤ *Advocacy Targets:*

- *Federal: advocates should work with HRSA and other federal agencies to advance the comprehensive and holistic models of care that have become the hallmark of Ryan White programs as health care reform is implemented, integrating Ryan White grantees and providers into both the Medicaid expansion and state exchanges; and develop recommendations for what Ryan White programs care and service delivery systems are replicable beyond HIV/AIDS services and should be used as a model for health care reform provisions (i.e., the “medical home” model).*
- *State: encourage Ryan White providers to integrate into Medicaid and state exchange provider networks and work with state Medicaid offices, state exchanges, and Ryan White grantees to ensure seamless transition to insurance expansions going into effect over the next five years.*

## **PHASE II: SECURING A BRIDGE TO 2014**

Currently, hundreds of thousands of people living with HIV and AIDS in the United States are uninsured or underinsured. Many will benefit from the new health care reform law, yet several of the key reform provisions do not go into effect until 2014. In the meantime, there is a health care access crisis, and the advocacy community needs to put pressure on policymakers to bridge the health care access gap experienced by far too many low-income individuals living with HIV and AIDS. The National HIV/AIDS Strategy provides a framework for some immediate advocacy targets.

## Implementing the National HIV/AIDS Strategy

In July 2010, the President announced a National HIV/AIDS Strategy (NHAS) and Implementation Plan, detailing goals and priorities to address the HIV/AIDS epidemic in the United States and providing a roadmap for drastically cutting the number of new HIV infections, increasing access to care and treatment, and reducing health disparities.<sup>16</sup> Though the implementation plan for expanding access to care and services is somewhat limited, there are several target areas in which the NHAS recommendations, if successfully implemented, will aid in efforts to close access to care gaps. Advocates will need to work with federal agencies, state health officials, and community-based organizations to implement NHAS provisions, for instance, supporting state applications for section 1115 Medicaid waivers to immediately expand Medicaid to cover pre-disabled people living with HIV and supporting health care workforce initiatives that include training of and support for HIV/AIDS health care providers.

### ➤ *Advocacy Targets:*

- *Federal: ensure that the promise of the NHAS is fulfilled by advocating for adequate funding for proposed implementation plans and working to make sure that the NHAS implementation plans complement health care reform implementation and immediately fill in gaps in access to care.*
- *State: work with state officials, particularly with Medicaid and AIDS directors, to ensure that they are aware of the implementation strategies of the NHAS and to provide guidance as they work to implement key provisions, for instance supporting section 1115 waiver applications.*

## Section 1115 Medicaid Waivers

Though the health care reform law largely eliminates the categorical eligibility rules that place people with HIV in a “catch-22” of having to wait until they are disabled by AIDS in order to be eligible for Medicaid coverage, the expansion does not take place until 2014. Low-income uninsured people living with HIV simply cannot wait until 2014 to gain access to life-saving care and treatment, especially given United States government treatment guidelines, which increasingly recognize the importance of providing early access to care. The NHAS implementation plan calls on CMS to “promote and support the development and expedient review of Medicaid 1115 waivers to allow States to expand their Medicaid programs to cover pre-disabled people living with HIV” by the end of 2010. Section 1115 waivers – and CMS support to states wishing to apply for and implement them – are critical to ensuring a bridge to access to care leading up to the Medicaid expansion in 2014. Importantly, active promotion and support of these waivers by the Centers for Medicare and Medicaid Services (CMS) is an implementation action item included the National HIV/AIDS Strategy.<sup>17</sup>

### ➤ *Advocacy Targets:*

- *Federal: encourage CMS to work with states to successfully develop Section 1115 Waivers for people living with HIV specifically by asking that CMS create a new waiver initiative under Section 1115 to help states provide temporary Medicaid coverage through 2014 similar to the initiative that was created in response to Hurricane Katrina; expedite the application and review process; send a letter to state officials alerting states to the option of applying for a section 1115 waiver; promote the waiver option on its website; organize a conference call (or series of calls) that will include state Medicaid Directors and AIDS Directors to discuss the*

*waiver option and address questions; appoint a designated CMS representative to provide technical assistance to states; and design a waiver template that includes what information states will need to provide to reach budget neutrality.*

- *State: encourage states to consider applying for a Section 1115 waiver.*

### **Early Treatment for HIV Act (ETHA)**

When health care reform's Medicaid expansion takes effect in 2014, Medicaid-based care and treatment will be available to all individuals below 133% of the federal poverty level (in 2010, \$14,404 for an individual/\$29,327 for a family of four).<sup>18</sup> However, low-income uninsured people living with HIV cannot wait until 2014 to gain access to life-saving care and treatment. ETHA would help to bridge the gap until 2014 by allowing states to immediately expand Medicaid access to pre-disabled people living with HIV and providing states with an enhanced federal FMAP.

➤ *Advocacy Target:*

- *Federal: continue to lobby Congress for enactment of ETHA.*
- *State: urge your congressional delegation and state leadership to endorse ETHA and promote its passage with your members of Congress.*

### **Enhanced Federal Funding of Medicaid Programs**

In order to stave off harmful cuts to state Medicaid programs at a time when more people needed Medicaid due to high rates of unemployment, the American Recovery and Reinvestment Act of 2009 provided states with enhanced federal funding of Medicaid programs. Though Congress voted to extend the enhanced federal matching rate another six months (to the end of June 2011), there is no indication that the unprecedented budget shortfalls states are currently facing will have abated by then.<sup>19</sup>

➤ *Advocacy Target:*

- *Federal: ensure that enhanced federal matching rates are continued to help states ride out the current economic crisis and avoid cutting needed Medicaid services.*
- *State: urge your Congressional delegation and state leadership to support enhanced federal matching rates.*

### **Emergency Supplemental ADAP Funding**

Significant increases in the number of low income people who are uninsured and must rely on AIDS Drug Assistance Programs (ADAPs) for access to life-saving medications have resulted in demand that far exceeds current funding levels. The result has been a rapidly increasing access to care and treatment crisis – in August 2010, waiting lists in 13 states totaled 2,937 individuals.<sup>20</sup> States have also enacted other cost-saving measures—for instance, limiting the ADAP drug formulary— that restrict access to needed medications.

➤ *Advocacy Targets:*

- *Federal: in FY2010, advocate for the \$126 million in federal emergency ADAP supplemental funding needed to eliminate waiting lists and reverse newly enacted cost-saving measures.*
- *State: urge states to provide necessary increases in state ADAP funding to avoid imposing waitlists and other cost-saving measures.*

## **Funding for Ryan White Programs**

Ryan White Programs are a primary source of medical care, treatment and support services for over half a million low-income individuals living with HIV and AIDS each year; however, despite ever-increasing numbers of people living with HIV and AIDS in the United States, federal funding of Ryan White programs has not kept up with need. These programs must be adequately funded to provide life-saving care to low-income people living with HIV and AIDS who will not be eligible for Medicaid until 2014.

➤ *Advocacy Targets:*

- *Federal: In order to meet the otherwise unmet care, treatment and service needs of people living with HIV and AIDS, Congress must provide adequate funding for Ryan White Programs (in FY2011, a \$3 billion increase, including \$1.2 billion for ADAP programs.)*

## **PHASE III: BEYOND HEALTH CARE REFORM: THE NEED FOR ONGOING ADVOCACY TO SECURE HEALTH CARE FOR PEOPLE LIVING WITH HIV AND AIDS**

Passage of health care reform was an historic and important step forward in the fight to expand access to health care in this country. However, even after all of the most important expansion provisions go into effect in 2014, there will still be gaps and limitations that need to be addressed. Within Medicaid alone, there is potential for substantial disparities between the benefits available to newly-eligible and already-eligible beneficiaries and the stringent citizenship requirements in place before reform remain a barrier for thousands of immigrants. Advocates must be aware of these gaps and limitations and work to ensure that access to care is a reality for everyone.

### **Additional Medicaid Reforms**

#### *Essential Health Benefits for All Medicaid Beneficiaries*

The health care reform law provides an essential health benefits package for all newly-eligible beneficiaries – individuals not eligible for Medicaid on the date of enactment of the law with income up to 133% of the federal poverty level.<sup>21</sup> These beneficiaries in all states are entitled to a benefit plan that includes, among other benefits, prescription drugs, preventive services, chronic disease management, mental health, and substance use services. Already-eligible beneficiaries – those enrolled in or eligible for Medicaid under pre-reform law on the date of enactment of the law – are not subject to the new essential health benefits package required for newly-eligible beneficiaries. Without a national, federally mandated benefits package for all beneficiaries, benefits will continue to vary dramatically by state. This difference is largely because, for already-eligible beneficiaries, there are different categories of Medicaid benefits, mandatory and optional. Under traditional Medicaid rules, for instance, physician services are among the mandated benefits, while prescription drug coverage is optional (though all states currently provide some sort of prescription drug coverage in their Medicaid programs).

➤ *Advocacy Targets:*

- *Federal: extend the federally-mandated essential health benefits package to all Medicaid beneficiaries.*
- *State: until enactment of a new federally-mandated benefits package, ensure that states provide a benefit package that meets the care and treatment needs of people living with HIV and AIDS; urge states not to pare back benefits or eligibility in order to fund expansion.*

*Provider Reimbursement Rates*

Current Medicaid reimbursement rates are shockingly low, and must be increased to ensure medical providers are willing and able to serve low-income clients. While the law increases primary care reimbursement rates for 2013 and 2014, this increase is temporary and not extended to specialists.<sup>22</sup>

➤ *Advocacy Targets:*

- *Federal: urge federal extension of increased reimbursement rates for Medicaid providers, including specialists, and ensure that when access to coverage expands in 2014, there is a permanent and sufficient reimbursement rate.*
- *State: monitor state reimbursement rate proposals and work with health care providers and others to ensure that rates meet the true cost of providing care and support access to needed services and providers.*

*Automatic FMAP Increase*

During economic crises, state tax revenues plummet at the same time as the number of those in need of and eligible for Medicaid increases dramatically.<sup>23</sup> Instead of waiting for Congress to act in times of economic crisis, an automatic increase in federal support should be tied to indicators of fiscal distress, like high unemployment.

➤ *Advocacy Targets:*

- *Federal: enact legislation for automatic enhanced FMAP during economic crisis.*

*Immigration Barriers to Access to Care*

Both now and after the eligibility expansion in 2014, legal immigrants still must endure a five-year waiting period to be eligible for Medicaid. This rule ensures that large gaps remain in access to care for low-income individuals, including those who are legally in the United States, working and paying taxes.

➤ *Advocacy Targets:*

- *Federal: rescind bans on access to public benefits for documented immigrant communities.*
- *State: ensure that state health officials and health centers are aware of and apply for grants available for community health centers through billions of dollars in health care reform funding.*

## **Re-conceptualization of and Continued Funding for Ryan White Programs**

With implementation of health care reform, thousands of individuals who previously received care and treatment through Ryan White programs will now access health care through Medicaid and new state insurance exchanges. It is clear that despite the tremendous possibilities of health care reform for individuals living with HIV and AIDS, major gaps in affordability and access to essential care, treatment, and services will remain. Even after full implementation of health care reform, Ryan White Programs will be necessary to fill these gaps.

➤ *Advocacy Target:*

- *Federal: ensure that Ryan White Programs are integrated into health care reform and remain adequately funded following the health care reform expansion, including working with HRSA to define ongoing need for Ryan White supported care, treatment and essential support services.*
- *State: work with Ryan White grantees to identify gaps and limitations in health care reform and ensure that Ryan White is able to provide a safety net and to fill these gaps.*

## **HIV/AIDS Testing and Linkage to Care**

The benefits to individual and public health from HIV testing and early intervention are numerous. However, the promise of early intervention is only realized if routine HIV testing and immediate access to care upon testing HIV positive are available. The NHAS includes the goal of significantly increasing testing and the proportion of newly diagnosed patients linked to clinical care within three months of diagnosis, and advocates should work with federal and state agencies to ensure that testing and care services are in place to meet this goal.

➤ *Advocacy Target:*

- *Federal: push for coverage of testing under Medicaid/Medicare and all private insurance plans; urge the U.S. Preventive Services Task Force to reconsider its recommendation supporting routine HIV testing only for persons who are determined to be at increased risk for HIV infection; and hold government officials accountable for meeting the NHAS implementation goal of combining increased testing with linkage to care.*
- *State: push for coverage of testing under Medicaid and all private insurance plans; and hold state government officials accountable for meeting the NHAS implementation goal of combining increased testing with linkage to care.*

## RESOURCES

Treatment Access Expansion Project (TAEP), at <http://www.taepusa.org>.

Health Care Reform Implementation Center, at <http://www.healthcare.gov/center/>.

Office of National AIDS Policy (ONAP), at <http://www.whitehouse.gov/administration/eop/onap>.

Kaiser Family Foundation, at <http://kff.org>.

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<sup>1</sup> Patient Protection and Affordable Care Act, § 1251(b). HHS issued a regulation on June 28, 2010 clarifying the PPACA's application to grandfathered plans. For example, actions that will cause a plan to lose grandfathered status include: significantly reducing benefits; significantly raising co-insurance charges, co-payment charges, or deductibles; and significantly lowering employer contributions. 45 CFR § 147.140; 29 CFR § 2590.715-1251; 26 CFR § 54.9815-1251T

<sup>2</sup> Patient Protection and Affordable Care Act, §§ 2001(c), 1302(b)(1).

<sup>3</sup> Health Care Implementation Center: Regulations & Guidance, at <http://www.healthcare.gov/center/regulations/index.html>.

<sup>4</sup> Patient Protection and Affordable Care Act, § 27063.

<sup>5</sup> Patient Protection and Affordable Care Act, § 10503.

<sup>6</sup> Health Center New Access Points Funded under the Affordable Care Act of 2010, at <https://grants.hrsa.gov/webExternal/FundingOppDetails.asp?FundingCycleId=450970E7-563E-4D2D-A021-5C775F7F614E&ViewMode=EU&GoBack=&PrintMode=&OnlineAvailabilityFlag=&pageNumber=&version=&NC=&Popup=>

<sup>7</sup> Patient Protection and Affordable Care Act, § 2713.

<sup>8</sup> U.S. Preventive Services Task Force, Screening for HIV Recommendations, at <http://www.uspreventiveservicestaskforce.org/uspstf05/hiv/hivrs.htm#clinical>.

<sup>9</sup> 45 CFR Part 147; 29 CFR Part 2590; 26 CFR Part 54.

<sup>10</sup> Affordable Care Act: Laying the Foundation for Prevention, at <http://www.healthreform.gov/newsroom/acaprevention.html>.

<sup>11</sup> National Alliance of State & Territorial ADAP Directors, HIV/Hepatitis Health Reform Watch (August 2010), at [http://www.nastad.org/Docs/Public/InFocus/2010811\\_Health%20Reform%20Watch%20Volume%203.pdf](http://www.nastad.org/Docs/Public/InFocus/2010811_Health%20Reform%20Watch%20Volume%203.pdf).

<sup>12</sup> Department of Health and Human Services, News Release: Sebelius Announces New \$250 Million Investment to Strengthen Primary Health Care Workforce, June 16, 2010, at <http://www.hhs.gov/news/press/2010pres/06/20100616a.html>.

<sup>13</sup> New Pre-Existing Condition Insurance Plan (PCIP), at <http://www.healthcare.gov/law/provisions/preexisting/index.html>.

<sup>14</sup> Id.

<sup>15</sup> Id.

<sup>16</sup> National HIV/AIDS Strategy (July 2010) and National HIV/AIDS Strategy Implementation Plan, at <http://www.whitehouse.gov/administration/eop/onap/nhas>.

<sup>17</sup> National HIV/AIDS Strategy Federal Implementation Plan (July 2010), available at <http://www.whitehouse.gov/files/documents/nhas-implementation.pdf>.

<sup>18</sup> Patient Protection and Affordable Care Act, § 2001(a)(1).

<sup>19</sup> Center on Budget and Policy Priorities, Survey: 46 States Have Faced Budget Shortfalls This Year (2010).

<sup>20</sup> National Alliance of State & Territorial ADAP Directors, ADAP Watch, at [www.nastad.org](http://www.nastad.org).

<sup>21</sup> Patient Protection and Affordable Care Act, § 2001.

<sup>22</sup> Health Care and Education Affordability Reconciliation Act of 2010, § 1202.

<sup>23</sup> Holahan, J. and Garrett, B., Rising Unemployment, Medicaid, and the Uninsured, prepared for the Kaiser Commission on Medicaid and the Uninsured (2009).

Healthcare Reform Law - Advisory Panels, Boards and Commissions

<i>Type of Program</i>	<i>Provision</i>	<i>Purpose</i>	<i>Requirements</i>
<p><u><a href="#">CO-OP Advisory Board</a></u> <b>§1322(b)(4)</b></p>	<p>The Comptroller General of the United States shall appoint 15 individuals with the necessary qualifications to serve on the advisory board. The board shall provide recommendations to the Secretary with respect to the CO-OP grant program. - <b>GAO</b></p>	<p>To provide recommendations to the Secretary with respect to the CO-OP grant program.</p>	<p>Individuals will be appointed by the Comptroller General of the United States and will be subject to certain qualification requirements. An appointed individual shall meet specified ethics requirements. The Advisory Board will either terminate once it completes its duties or by December 31, 2015. 15 members of the CO-OP Advisory Board were appointed on 6/23/2010.</p>
<p><u><a href="#">Medicaid and CHIP Payment and Access Commission (MACPAC)</a></u> <b>§2801</b></p>	<p>Legislation makes improvements to MACPAC and provides the commission with additional regulatory authority.-MACPAC shall review Medicaid and CHIP regulations and may comment through submission of a report to Congress and the Secretary. In submitting recommendations, MACPAC shall also consult with States. MACPAC shall consult with MedPAC with respect to Medicaid beneficiaries that are dually eligible for Medicaid and Medicare. \$11 million in funding is provided for FY 2010 - <b>GAO</b></p>	<p>To improve the quality, efficiency, and cost of health services provided by Medicaid and CHIP.</p>	<p>MACPAC members will include individuals who have had direct experience as enrollees and individuals with national recognition for expertise in Federal safety net health programs, health finance, actuarial science, integrated delivery systems, reimbursement for health care, HIT, and other providers who provide a mix of different services. 17 MACPAC members were appointed on 12/23/2009. The terms are staggered with the first members' terms expiring December 2010.</p>
<p><u><a href="#">Advisory Panel for the Early Childhood</a></u></p>	<p>The HHS Secretary shall establish an advisory panel for the purpose</p>	<p>To help entities develop and implement improvement plans</p>	<p>The Secretary shall establish this panel.</p>

<p><u>Home Visitation Program (Program Implementation)</u> §2951, adding §511 of the SSA</p>	<p>of obtaining recommendations regarding the level of technical assistance that is needed to help institute improvement plans for eligible entities. – <b>HRSA/ACF</b></p>	<p>with respect to the Early Childhood Home Visitation Program.</p>	
<p><u>Advisory Panel for the Early Childhood Home Visitation Program (Program Design)</u> §2951, adding §511(g)(1) of the SSA</p>	<p>The HHS Secretary shall appoint an independent advisory panel consisting of experts in early childhood development, education, and program evaluation and research. - <b>HRSA/ACF</b></p>	<p>To review, and make recommendations on, the design and plan for the required evaluation of the program; to maintain and advise the Secretary regarding the process of the evaluation; and to comment on the Secretary’s report to Congress.</p>	<p>The Secretary shall establish this panel, which shall make recommendations by 2011.</p>
<p><u>Quality Measurement Selection</u> §3014</p>	<p>Multi-stakeholder groups shall convene to provide input on the HHS selection of quality measures. - <b>HHS</b></p>	<p>To provide input on the selection of quality measures.</p>	<p>Individuals selected shall be subject to public nomination and public comment. Beginning in 2012, multi-stakeholder groups shall report recommendations to the Secretary by February 1.</p>
<p><u>CMS Innovation Center (CMI)</u> §3021(a)(3)</p>	<p>In carrying out its duties, CMI shall consult with representatives of relevant Federal agencies and clinical and analytical experts with expertise in medicine and health care management. The CMI shall also use open door forums and other mechanisms to seek input from interested parties. - <b>CMS</b></p>	<p>To establish an innovation center within CMS that tests payment and delivery models that reduce expenditures and enhance quality of care furnished. The innovation center has \$10 billion to spend over the next decade in a quest for the best ways of improving care and reducing costs</p>	<p>Stakeholder involvement is subject to the Secretary and members of the CMI. CMI must be carrying out its responsibilities by 2011.</p>
<p><u>Independent Payment Advisory Board</u></p>	<p>The Secretary shall establish an Independent Payment Advisory Board to present proposals to</p>	<p>To improve the quality of care for beneficiaries, reduce the per capita rate of growth in Medicare</p>	<p>The Board shall present proposals to Congress that may modify provider or supplier payments for</p>

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<p><b>§3403, adding §1899A to the SSA</b></p>	<p>Congress that reduce Medicare expenditures. Legislation provides \$15 million in FY 2012 for the Board to carry out its duties. Funding for subsequent years is increased by the annual percentage increase in CPI for all urban consumers. - <b>CMS</b></p>	<p>spending and to extend Medicare solvency.</p>	<p>payment years 2015 and beyond. The Board shall present proposals to Congress that modify payments for hospitals for payment years 2020 and beyond. The Board shall be composed of 15 members appointed by the President by and with the advice and consent of the Senate. Appointees shall include individuals with national recognition for their expertise in health finance and economics, actuarial science, health facility management, health plans and integrated systems, reimbursement to health facilities, allopathic and osteopathic physicians, and other providers who provide a mix of different professions, broad geographic representation, and a balance between urban and rural communities. Members serve for six years, except that of the members first appointed to create the Board, five will be appointed for a term of 1 year, five will be appointed for a term of three years, and five will be appointed for a term of six years, so that terms of Members will expire in three staggered classes. A member may not serve more than two full consecutive terms.</p>
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<p><b><i>Consumer Advisory Council</i></b>  <b><i>§3403(k), adding §1899A(k) to the SSA</i></b></p>	<p>There is established a consumer advisory council to advise the Independent Medicare Advisory Board on the impact of payment policies with respect to consumers.  - CMS</p>	<p>To advise the Independent Medicare Advisory Board on the impact of payment policies with respect to consumers.</p>	<p>The Council shall be composed of 10 consumer representatives appointed by the Comptroller General of the United States (one member from among each of the 10 regions established by the Secretary). Members of the Council shall represent the interests of consumers and identified communities.</p>
<p><b><i>Medication Therapy Management (MTM) Services</i></b>  <b><i>§3503(e), adding §935 to the PHSA</i></b></p>	<p>In establishing MTM services grant program, the HHS Secretary shall consult with identified stakeholders. - CMS</p>	<p>To ensure best practices with respect to the MTM grant program.</p>	<p>Identified stakeholders include Federal, State, private entities, public-private entities, academic entities, pharmacy and pharmacist organizations, health care organizations, consumer advocates, chronic disease groups, and other stakeholders involved with the research and implementation of MTM services.</p>
<p><b><i><u>National Prevention, Health Promotion, and Public Health Council</u></i></b>  <b><i>§4001(a)-(d)</i></b></p>	<p>The President shall establish within HHS the National Prevention, Health Promotion, and Public Health Council. – HHS</p>	<p>To coordinate policies at the Federal level with respect to quality of health care and to develop a national prevention, health promotion, public health and integrative health strategy.</p>	<p>The President shall appoint the Surgeon General to serve as the chairperson of the Council. The Council shall be composed of the HHS Secretary, the Agriculture Secretary, the Education Secretary, the Chairman of the FTC, the Transportation Secretary, the Labor Secretary, the DHS Secretary, the Administrator of the EPA, the Director of the Office of National Drug Control, the Assistant Secretary for Indian</p>

Affairs, the Chairman of the Corporation for National and Community Service, and heads of other Federal agencies that the chairperson determines appropriate. The Council shall provide coordination at the Federal level and develop a national prevention, health promotion, public health and integrative health strategy. The Council shall establish a process to allow public input on an ongoing basis.

[Advisory Group on Prevention Health Promotion, and Integrative and Public Health](#)

**§4001(f)**

The President shall establish an Advisory Group on Prevention Health Promotion, and Integrative and Public Health. - **HHS**

To consult with the National Prevention, Health Promotion, and Public Health Council in developing a national prevention, health promotion and public health strategy.

The Advisory Group shall develop policy and program recommendations and advise the Council on lifestyle-based chronic disease prevention and management, integrative health care practices, and health promotion. The Advisory Group shall be composed of no more than 25 non-Federal members to be appointed by the President. The President shall ensure that the Advisory Group includes a diverse group of licensed health professions, including integrative health practitioners who have expertise in worksite health promotion, community services, preventive medicine, health coaching, public health education,

			geriatrics, and rehabilitation medicine.
<b><i>Independent Preventive Services Task Force</i></b> <b>§4003(a)</b>	The Director of the CDC shall convene an Independent Preventive Services Task Force. Legislation provides such sums as may be necessary for each fiscal year to carry out the activities of the task force. - <b>CDC</b>	To develop recommendations for the health care community and update previous clinical preventive recommendations.	The Task Force shall be composed of individuals with appropriate expertise. The Task Force shall review the scientific evidence related to the effectiveness, appropriateness, and cost-effectiveness of clinical preventive services.
<b><i><u>Community Preventive Services Task Force</u></i></b> <b>§4003(b), adding §399U to the PHSA</b>	The Director of the CDC shall convene an independent Community Preventive Services Task Force. Legislation provides such sums as may be necessary for each fiscal year to carry out the activities of the task force. - <b>CDC</b>	To develop recommendations that will be published in the Guide to Community Preventive Services.	The Task Force shall be composed of individuals with appropriate expertise. The Task Force shall review the effectiveness, appropriateness, and cost-effectiveness of community preventive intervention.
<b><i>Advisory Council for Epidemiology-Laboratory Capacity Grants</i></b> <b>§4304, adding §2821(a)(3) of the PHSA</b>	The CDC Director shall establish an advisory council with respect to epidemiology-laboratory capacity grants. - <b>CDC</b>	To assist public health agencies in improving surveillance for, and response to, infectious diseases and other conditions.	The CDC Director shall appoint the advisory council.
<b><i><u>Interagency Pain Research Coordination Committee</u></i></b> <b>§4305, adding §409J(b) of the PHSA</b>	The Secretary shall establish and maintain as necessary a committee, to be known as the Interagency Pain Research Coordinating Committee. - <b>NIH</b>	To coordinate all efforts within the Department of HHS and other Federal agencies that relate to pain research.	The Secretary shall establish this committee by 2011. The committee shall be composed of not more than 7 voting Federal representatives appointed by the Secretary from agencies that conduct pain research and treatment and 12 additional voting

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members. Additional voting members include 6 non-Federal members, which shall be appointed from among scientists, physicians, and other health professionals, and 6 members appointed by the public who are representatives of leading research, advocacy, and service groups for individuals with pain conditions.

National Health Care Workforce Commission  
§5101(a)-(d)

There is established a National Health Care Workforce Commission. Legislation authorizes such sums as may be necessary to establish and maintain the Commission. - **GAO**

To serve as a national resource for Congress, the President, States, and localities regarding America's health care workforce.

The Commission shall be composed of 15 members to be appointed by the Comptroller General. Members of the Commission shall have national recognition in health care labor market analysis, health care finance, health care facility management, health care plans and integrated delivery systems, health workforce education and training, and health care philanthropy. Members will also include providers of health care services and individuals in related fields. Membership of the Commissions shall include no less than one representative of the health care workforce, employers, small businesses, third-party payers, individuals skilled in the conduct and interpretation of health care services, representatives of

			consumers, labor unions, State or local workforce investments boards, and educational institutions.
<b><i>The Commission on Key National Indicators §5605(b)-(c)</i></b>	There is established a Commission on Key National Indicators. - <b>Congress</b>	To establish a Commission on Key National Indicators that conducts comprehensive oversight of a newly established key national indicators system; make recommendations on how to improve the system; and coordinate with Federal Government users and information providers.	The Commission shall be composed of 8 members, to be appointed equally by the majority and minority leaders of the Senate and the Speaker and minority leader of the House of Representatives. Members of the Commission shall not include Members of Congress or other elected Federal, State, or local government officials. In making appointments, members of Congress shall appoint individuals who have shown a dedication to improving civic dialogue and decision-making through the wide use of scientific evidence and factual information. Members of the Commission shall be appointed no later than 2010.
<b><i><u>Advisory Panels for the Patient-Centered Outcomes Research Institute</u></i></b> <b><i>§6301, adding §1181 of the SSA</i></b>	The Institute may appoint permanent or ad hoc expert advisory panels as determined appropriate. - <b>GAO</b>	To assist in identifying research priorities and establishing the research project agenda.	Such advisory panels will focus on clinical trials and rare diseases. Advisory panels shall include representatives of practicing research clinicians, patients, and experts in scientific and health services research, health services delivery, and evidence-based medicine who have experience in

			<p>the relevant topic. As appropriate, advisory panels shall also include experts in integrative health and primary prevention strategies.</p>
<p><a href="#"><u>Patient-Centered Outcomes Research Institute Methodology Committee</u></a> <i>§6301, adding §1181(d)(1)(6) of the SSA</i></p>	<p>The Institute shall establish a standing methodology committee to carry out certain functions. - <b>GAO</b></p>	<p>To develop and improve the science and methods of comparative clinical effectiveness research.</p>	<p>The committee shall be composed of not more than 15 members appointed by the Comptroller General of the United States. Members appointed to the Committee shall be experts in their scientific field, such as health services research, clinical research, comparative clinical effectiveness research, biostatistics, genomics, and research methodologies. Stakeholders with such expertise may be appointed to the Committee. The Committee shall be established by 2012. In developing methodological standards, the Committee shall allow input from relevant experts and stakeholders.</p>
<p><a href="#"><u>Board of Governors for the Patient-Centered Outcomes Research Institute</u></a> <i>§6301, adding §1181(f) of the SSA</i></p>	<p>The Institute shall have a Board of Governors. - <b>GAO</b></p>	<p>To carry out the duties of the Patient-Centered Outcomes Research Institute.</p>	<p>The Board shall consist of the Director of AHRQ, the Director of NIH, and 17 appointed members. The appointed members shall include: 3 members representing patients and health care consumers; 7 members representing physicians and providers, including at least 4 physicians, 1 surgeon, 1 nurse, 1</p>

			<p>State-licensed integrative health care practitioner, and an individual representing a hospital; 3 members representing private payers, of whom at least 1 member shall represent health insurers and at least 1 member shall represent employers who self-insure employee benefits; 3 members representing pharmaceutical device, and diagnostic manufacturers; 1 member representing quality improvement or independent health service researchers; and 2 members representing the Federal Government or the States, including at least 1 member representing a Federal health program.</p>
<p><u><a href="#">The Elder Justice Coordinating Council</a></u>  <b>§6703, adding §2021 of the SSA</b></p>	<p>The Secretary shall establish the Elder Justice Coordinating Council. Legislation authorizes such sums as may be necessary. - <b>HHS</b></p>	<p>To make recommendations to the Secretary for the coordination of activities of the HHS, the Department of Justice, and other relevant Federal State, local, and private agencies and entities relating to elder abuse, neglect, exploitation, and other crimes against seniors.</p>	<p>The Council shall be composed of the HHS Secretary, the Attorney General, and the head of each Federal department or agency.</p>
<p><u><a href="#">Advisory Board on Elder Abuse, Neglect, and Exploitation</a></u>  <b>§6703, adding §2022</b></p>	<p>There is established a board to be known as the Advisory Board on Elder Abuse, Neglect, and Exploitation. – <b>HHS/AOA</b></p>	<p>To create short-and long-term multidisciplinary strategic plans for the development of the field of elder justice and to make</p>	<p>The Advisory Board shall be composed of 27 members appointed by the HHS Secretary from among members of the</p>

<p><i>of the SSA</i></p>	<p>recommendation so the Elder Justice Coordinating Council.</p>	<p>general public who are individuals with experience and expertise in elder abuse, neglect, and exploitation prevention, detection, treatment, intervention, and prosecution. The Secretary shall publish a notice in the Federal Register soliciting nominations for the appointment of members of the Advisory Board.</p>
<p><a href="#"><u>The Community Living Assistance Services and Supporters (CLASS) Independence Advisory Council</u></a>  <b>§8002, adding §3207 of the PHSA</b></p>	<p>In developing and carrying out the CLASS benefit program, the HHS Secretary shall establish and consult with the CLASS Independence Advisory Council. - <b>HHS</b></p>	<p>To make improvements and modifications to the CLASS benefit program.</p> <p>The Council shall evaluate alternative benefit plans and recommend for designation as the CLASS Independence Benefit Plan for offering to the public the plan that the Council determines best balances price and benefits to meet enrollees’ needs in an actuarially sound manner, while optimizing the probability of the long-term sustainability of the CLASS program. The Council shall be composed of not more than 15 individuals appointed by the President. A majority of members shall be representatives who participate or are likely to participate in the CLASS program and representatives of older and younger workers, individuals with disabilities, family caregivers of individuals who require services and supports to maintain their</p>

			independence at home or in another residential setting of their choice in the community. Members shall also include individuals with expertise in long-term care or disability insurance, actuarial science, economics, and other relevant disciplines as determined by the Secretary.
<b><i>Board of Trustees for the CLASS Independence Fund</i></b>  <b><i>§8002, adding §3206(c) of the PHSA</i></b>	There is hereby created a body to be known as the Board of Trustees. - <b>HHS</b>	To hold the CLASS Independence Fund and report to Congress on the CLASS program.	The Board shall be composed of the Secretary of Treasury, the Secretary of Labor, the HHS Secretary and two members of the public who shall be nominated by the President subject to confirmation by the Senate.
<b><i><u>Personal Care Attendants Workforce Advisory Panel</u></i></b>  <b><i>§8002, adding §3210(c) of the PHSA</i></b>	The HHS Secretary shall establish a Personal Care Attendants Workforce Advisory Panel. - <b>HHS</b>	To examine and advise the Secretary and Congress on workforce issues related to personal care attendant workers.	The Secretary shall appoint members of the panel by 2011. Members shall include individuals with disabilities of all ages, seniors, representatives of individuals with disabilities, representatives of senior individuals, representatives of workforce and labor organizations, representatives of home and community-based service providers, and representatives of assisted living providers.
<b><i><u>Cures Acceleration Network Review Board</u></i></b>	There is established a Cure Acceleration Network Review Board. - <b>NIH</b>	To advise the Director of NIH on the conduct of the activities of the Cure Acceleration Network.	The Board shall be comprised of 24 members who are appointed by the Secretary and who serve at the pleasure of the Secretary. The

***§10409, adding  
§402C(d) of the  
PHSA***

Secretary shall appoint individuals to the Board based solely on the individual's established record of distinguished service in the following areas: basic research; medicine; biopharmaceuticals; discovery and delivery of medical products; bioinformatics and gene therapy; medical instrumentation; and regulatory review and approval of medical products. The Secretary shall select at least 1 individual who is eminent in such fields. At least 4 individuals shall be recognized leaders in professional venture capital or private equity organizations and have demonstrated experience in private equity investing. At least 8 individuals shall represent disease advocacy organizations. In addition to the 24 Board members, the Secretary shall appoint ex-officio members of the Board from Federal departments.

***[Advisory Committee  
for Breast Health and  
Cancer](#)***

The Director of CDC shall establish an advisory committee with respect to Breast Health and Cancer. - CDC

To assist in creating and conducting a Breast Cancer Awareness education campaign.

The Director shall appoint such members as deemed necessary to properly advise the Secretary. Such individuals and organizations shall have expertise in breast cancer, disease prevention, early detection, diagnosis, public health, social marketing, genetic screening

***§10413, adding  
§399NN(a)(4) of the  
PHSA***

			and counseling, treatment, rehabilitation, palliative care, and survivorship in young women. The Director shall appoint these individuals within 60 days after the enactment of the legislation.
<b><i>Interagency Task Force to Assess and Improve Access to Health Care in the State of Alaska</i></b> <b>§5104</b>	There is established a task force to be known as the Interagency Access to Health Care In Alaska Task Force. - <b>HHS</b>	To assess access to health care for beneficiaries of Federal health care systems in Alaska.	The Task Force shall be comprised of Federal members appointed not later than 45 days after the date of enactment.
<b><i>Review Panel for the Evaluation of Alternatives to Current Medical Tort Litigation</i></b> <b>§10607, adding §399V-4(d)(2) of the PHSA</b>	The Comptroller General shall solicit nominations from the public for individuals to serve on the review panel. - <b>GAO</b>	To evaluate alternatives to current medical tort litigation.	The Comptroller General shall appoint, at least 9, but not more than 13, highly qualified individuals to serve on the review panel. The Comptroller General shall ensure that the following entities receive fair representation on such panel: patient advocates; health care providers and health care organizations; attorneys with expertise in representing patients and health care providers; medical malpractice insurers; state officials; and patient safety experts.