CAEAR Coalition
June 2011 Membership Meeting
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COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF

CAEAR COALITION

Ryan White Program Appropriations

Program	FY 2010 Final	FY 2011Final[1]	CAEAR Coalition FY 2012 Request	President's FY 2012 Budget Request
Part A	$679.1m (+$16m)	$677.7m (-$0.4m)	$751.9m (+$74.2m)	$679.1m (+$1.4m)
Part B Base	$418.8m (+$10m)	$418.0m (-$0.8m)	$494.8m (+$76.8m)	$418.8m (+$0.8m)
Part B ADAP	$858.0m[2] (+$18m)	$885.0m (+$27m)	$991.0m (+$106.0m)	$940.0m (+$55.0m)
Part C	$206.8m (+$4.9m)	$205.6m (-$0.8m)	$272.2m (+$66.6m)	$211.5m (+$5.9m)
Part D	$77.8m (+$0.9m)	$77.3m (-$0.3m)	$83.1m (+$5.8m)	$77.8m (+$0.5m)
Part F AETC	$34.8m (+$0.4m)	$34.6m (-$0.1m)	$50.0m (+$15.4m)	$34.8m (+$0.2m)
Part F Dental Reimb.	$13.6m (+$0.2m)	$13.5m (-$0.1m)	$19.0m (+$5.5m)	$13.6m (+$0.1m)

1. Amounts reflect 0.2% budget-wide tap.
2. ADAP received an additional $25 million as emergency funding for FY2010. $2 million of the $25 million emergency funding were expired unobligated Ryan White funds and not counted in the appropriated total. The total amount awarded to states was $860 million

Submitted on behalf of CAEAR Coalition:

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On behalf of the tens of thousands of individuals living with HIV/AIDS to whom members of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition provide care, I thank Chairman Rehberg and Ranking Member DeLauro for affording us the opportunity to submit testimony regarding increased funding for the Ryan White HIV/AIDS Program**.**

The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition is a national membership organization which advocates for sound federal policy, program regulations, and sufficient appropriations to meet the care, treatment, support service and prevention/wellness needs of people living with HIV/AIDS and the organizations that serve them, focusing on ensuring access to high quality health care and the evolving role of the Ryan White Program.

A Wise Investment in a Program That Works

The Ryan White Program works. In its Program Assessment Rating Tool (PART), the White House Office of Management and Budget (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." Even more impressively, OMB'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." **Out of the 1,016 federal programs rated—98% of all federal programs—the Ryan White Program was one of seven that received a score of 100% in "Program Results and Accountability."**

The Ryan White Program serves as the indispensable safety net for thousands of low-income, uninsured or underinsured people living with HIV/AIDS.

- Part A provides much-needed funding to the 52 major metropolitan areas hardest hit by the HIV/AIDS epidemic with severe needs for additional resources to serve those living with HIV disease in their communities.
- Part B assists states and territories in improving the quality, availability, and organization of health care and support services for individuals and families with HIV.
- The AIDS Drug Assistance Program (ADAP) in Part B provides life-saving, urgently needed medications to people living with HIV/AIDS in all 50 states and the territories.
- Part C provides grants to 349 faith- and community-based primary care health clinics and public health providers in 49 states, Puerto Rico and the District of Columbia. These clinics play a central role in the delivery of HIV-related medical services to underserved communities, people of color, and rural areas where Part C funded clinics provide the only HIV specific medical services available in the region.

- Part F AETC supports training for health care providers to identify, counsel, diagnose, treat, and manage individuals with HIV infection and to help prevent high-risk behaviors that lead to infection. It has 130 program sites with coverage in all 50 states.

CAEAR Coalition's FY 2012 funding requests for Part A, Part B base and ADAP, and Part C reflect the amounts authorized by Congress in the most recent authorization of the program.

There continues to be an increasing gap between the number of people living with HIV/AIDS in the U.S. in need of care and the federal resources available to serve them. Between 2001 and 2008 the number of people living with AIDS grew 35% and yet funding for medical care and support services in communities with the greatest burden of HIV disease grew less than 12% between 2001 and 2010. Similarly, funding for Part C–funded, faith and community-based primary care clinics, which provide medical care for people living with HIV/AIDS in remote, rural and geographically isolated, urban communities nationwide, grew by only 11% between 2001 and 2010 as the number of people they care for grew by 52%. The authorized amounts we request would not fully address these funding deficiencies, but would begin to reduce the still growing gaps in funding.

We thank you in advance for your consideration of our comments and our request for:

- $751.9 million for Part A to support grants to the cities where most people with HIV/AIDS live and receive their care and treatment.
- $495 million for Part B base to provide additional needed resources to the states to bolster the public health response statewide regardless of location.
- $991 million in funding for the ADAP line item in Part B so uninsured and underinsured people with HIV/AIDS can access the anti-HIV and other prescribed medications they need to survive.
- $272.2 million for Part C to support grants to faith- and community-based organizations, health care agencies, and clinics.
- $50 million to fund the 11 regional centers funded under by Part F AETC to offer specialized clinical education and consultation to frontline providers.

Sufficient Funding for Ryan White Programs Saves Money and Saves Lives

Increased funding for Ryan White Programs will reap a significant health return for minimal investment. Data show that Part A and Part C programs have reduced HIV-related hospital admissions by 30 percent nationally and by up to 75 percent in some locations. The programs supported by the Ryan White HIV/AIDS Program also have been critical in reducing AIDS mortality by 70 percent. The Ryan White Program works, resulting in both economic stimulus and social savings by helping keep people, stable, healthy and productive.

Growing Needs as More Tested and Entering Care

The Centers for Disease Control and Prevention (CDC) estimates that as of 2006 there were 1,106,400 persons living with HIV/AIDS in the U.S. Approximately one-half were not in care and receiving treatment. New CDC recommendations for routine HIV testing have increased the

influx of newly diagnosed individuals into care, but with 56,000 newly diagnosed individuals per year, the federal resources have not kept pace with the burgeoning need.

The FY 2012 appropriation presents a crucial opportunity to provide the Ryan White Program with the levels of funding needed to address a growing epidemic in young men, as the CDC continues to increase efforts to expand HIV testing so people living with HIV know their status, control their health, and protect others.

CAEAR Coalition supports efforts to help individuals infected with HIV learn their status at the earliest possible time. However, CAEAR Coalition is concerned about the unmet demand for services created by insufficient resources at the federal level. Researchers estimate that CDC's expanded HIV testing guidelines will bring an additional 46,000 people into care over five years and significantly reduce the 21% of people living with HIV who do not know they are infected and therefore are not in care. Bringing these individuals into care will save large sums of money in the long run, but requires an initial investment now. **Research clearly shows that averting a single HIV infection saves $221,365 in lifetime health care costs[1], and getting people on anti-HIV treatment early lowers levels of HIV circulating in the body and reduces potential transmissions[2]—saving lives and money in the long term—but we must invest now in care and treatment to reap those rewards.** Caring for individuals early in their disease will increase the cost of care by $2.7 billion over five years and the majority of those costs will fall to federal discretionary programs like the Ryan White Program and will not be offset by entitlement programs.[3]

Community-based providers are stretched to provide high-quality care with the scarce resources available. CAEAR Coalition is concerned that many HIV expert medical staff are scheduled to retire and the persistent financial pressures may accelerate the loss of trained professionals in the field. This additional pressure on an already overburdened system will leave many of the more than 200,000 HIV-infected individuals who do not know their HIV status without access to the care they need.

State budget cuts have created a continuing and growing ADAP funding crisis as a record number of people are in need of ADAP services due to the economic downturn. As of April 2011, there are 7,900 people on ADAP waiting lists in 11 states. Additionally, ADAP waiting lists and other cost-containment measures, including limited formularies, reducing eligibility, or removing already enrolled people from the program, are clear evidence that the need for HIV-related medications continues to outstrip availability. ADAPs are forced to make difficult trade-offs between serving a greater number of people living with HIV/AIDS with fewer services or serving fewer people with more services. Additional resources are needed to reduce and prevent further use of cost-containment measures to limit access to ADAPs and to allow all state ADAPs to provide a full range of HIV anti-retrovirals and treatment for opportunistic infections.

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[1]Holtgrave DR, Briddell K, Little E, Bendixen AV, Hooper M, Kidder DP, et al. Cost and threshold analysis of housing as an HIV prevention intervention. *AIDS & Behavior*.(2007)11(Suppl 2), S162-S166.

[2]Montaner J, Lima VD, Barrios R, et al. Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: a population-based study. *The Lancet* (2010) 376(9740): 532-539.

[3] Martin EG, Paltiel AD, Walensky, RP, Schackman BR, Expanded HIV Screening in the United States: What Will It Cost Government Discretionary and Entitlement Programs? A Budget Impact Analysis. *Value in Health* (2010) 13: 893–902.

The number of clients entering the 349 Part C community health centers and outpatient clinics has consistently increased over the last five years. Over 247,000 unduplicated persons living with HIV/AIDS receive medical care in Part C–funded community health centers and clinics each year. These faith- and community-based HIV/AIDS providers are staggering under the burden of treatment and care after years of funding cuts prior to the modest increase in recent years. The success of the CDC's routine HIV testing recommendations has generated new clients for Part C–funded health centers and clinics too, but unfortunately with no increase in funding to provide the high quality health care services and treatment access people with HIV/AIDS require.

Ryan White-Funded Programs are Economic Engines in their Communities

Ryan White-funded programs, including many community health centers, are small businesses providing jobs, vendor contracts and other types of economic development to low-income, urban and rural communities, frequently serving as anchors for existing and new businesses and investments. These organizations employ people in their communities, providing critical entry-level jobs, community-based training and career building.

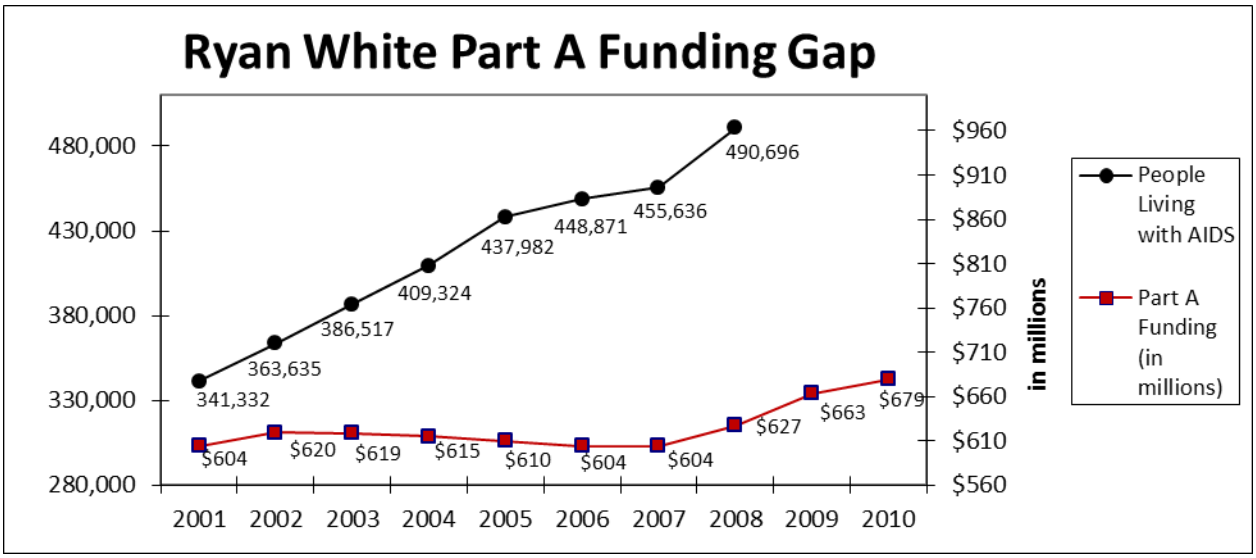
For example, a large, urban community health center brings an estimated economic impact of $21.6 million, employing 281 people, and a small, rural health center has an estimated economic impact of $3.9 million, employing 52 people. Investing in AIDS care and treatment is an investment in jobs and community development in communities that need it most.

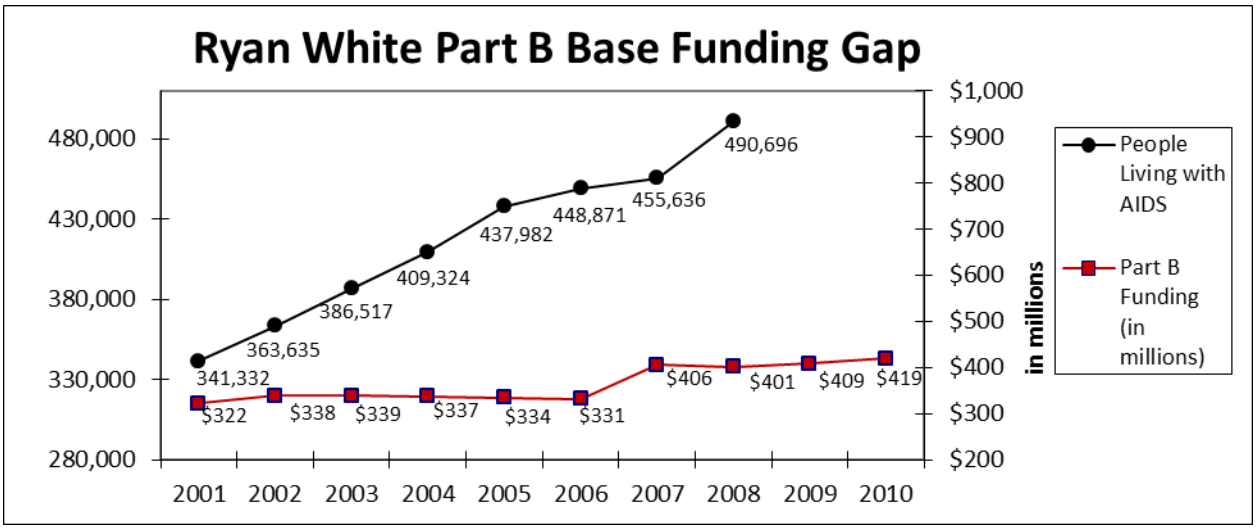
Ryan White Program Key to Meeting the Goals of the National HIV/AIDS Strategy

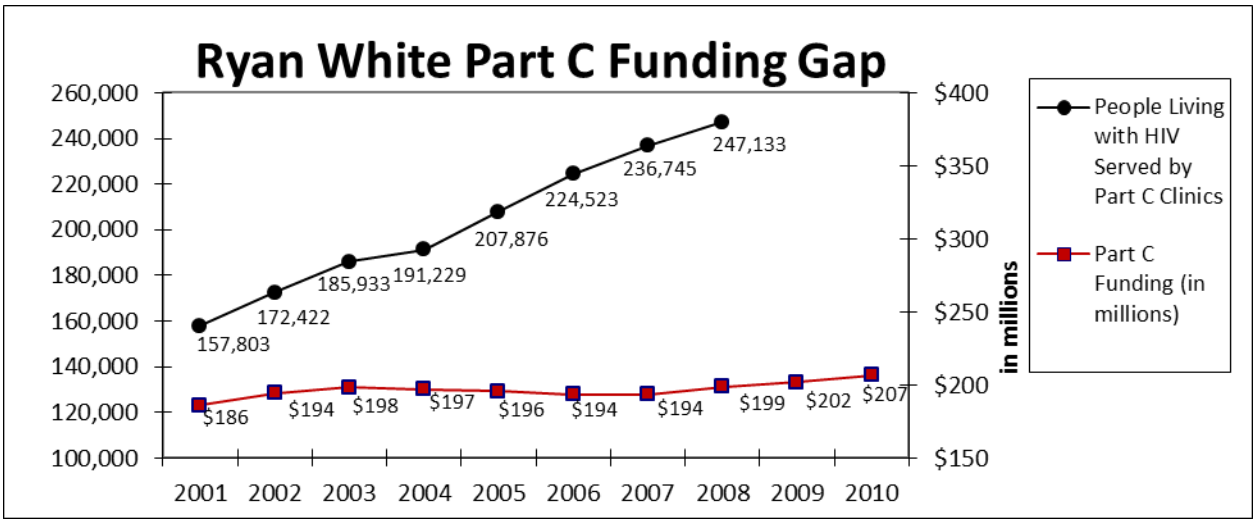
CAEAR Coalition is eager to work with Congress to meet the challenges posed by the HIV/AIDS epidemic. In 2012, we have the collective chance to implement the community-embraced health care goals and policies in the National HIV/AIDS Strategy (NHAS). The National Strategy is an opportunity to reinvigorate the nation's response to the HIV/AIDS epidemic and stop its relentless movement into our communities. The Ryan White HIV/AIDS Program is key to reaching the NHAS goals of reducing new HIV infections, increasing access to care and improving health outcomes for people living with HIV/AIDS, and reducing HIV-related health disparities. Ryan White 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—suggesting the programs and resources are targeted to underserved and marginalized populations. Early care and treatment are more critical than ever because we can help those infected learn their status and get into care and treatment in order to improve their own health and the health of their communities.

The Ryan White Program's history of accomplishments for public health and people living with HIV/AIDS is a wonderful legacy for the U.S. Congress. There continues to be a vast need for additional resources to address the health care and treatment needs of people living with HIV across the country. In recognition of its high level of effectiveness and validation over time from credible federal government institutions, CAEAR urges the committee to provide the Ryan White HIV/AIDS Program with the funding levels authorized by Congress for Fiscal Year 2012.

Growing HIV/AIDS Funding Gaps, 2001-2010







COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR COALITION

Increased Ryan White Program Resources Needed in 2012 to Respond to Growing Need for Care

The Need for HIV/AIDS Care and Treatment is Growing

- CDC has significantly increased efforts to **expand HIV testing in hard-hit communities** to help people living with HIV learn their status and enter care.

- **Researchers estimate that CDC's expanded HIV testing guidelines will bring an additional 46,000 people into care over five years** and reduce the 21% of people living with HIV but not in care. Bringing these individuals into care will save money in the long run, but requires an initial investment now–caring for individuals early in their disease will **increase the cost of care by $2.7 billion over five years and the majority of those costs will fall to federal discretionary programs like the Ryan White Program** and will not be offset by entitlement programs.[1]

- **45% of HIV-infected people in the U.S. for whom antiretroviral therapy would likely be recommended are not-accessing treatment**–together, primary medical care and medications are key to helping people living with HIV maintain their health. [2]

The Ryan White Program Works

- The OMB's Program Assessment Rating Tool (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.**

- The PART assessment 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.

- The program **addresses disparities in access to HIV treatment and care,** serving women and racial and ethnic minorities in significantly higher proportions than their representation among reported AIDS cases.

Ryan White-Funded Programs are Economic Engines in their Communities

- Ryan White-funded programs, including many community health centers, bring jobs and economic development to low-income urban communities and sparsely populated rural areas, serving as anchors for existing and new businesses and investments. These organizations employ people in their communities, providing critical entry-level jobs and community-based training and career building.

- A large, urban community health center brings an estimated economic impact of $21.6 million, employing 281 people, and a small, rural health center has an estimated economic impact of $3.9 million, employing 52 people.[3]

State Budget Cuts Have Created an Immediate Funding Crisis

- The AIDS Drug Assistance Programs (ADAPs) in many states are on the brink of the worst funding shortfall in many years and there is a record number of people in need of ADAP services due to the economic downturn. Adjustments have been made to Medicaid reimbursement rates to address economic conditions but no similar steps have been taken for ADAP.

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[1] Martin, E. G., Paltiel , A. D., Walensky, R. P. and Schackman, B. R. (2010), Expanded HIV Screening in the United States: What Will It Cost Government Discretionary and Entitlement Programs? A Budget Impact Analysis. Value in Health, 13: 893–902. http://www.ncbi.nlm.nih.gov/pubmed/20950323

[2] Kates J. Insurance Coverage and Access to HIV Testing and Treatment: Considerations for Individuals at Risk for Infection and for Those with Undiagnosed Infection. Clinical Infectious Diseases, 2007:45 (Suppl 4). http://cid.oxfordjournals.org/content/45/Supplement_4/S255.full

[3] National Association of Community Health Centers, Access Granted, August 2007. http://www.nachc.com/research

- **8,310 people in 13 states are on waiting lists for the program**. **17 states have cost-containment strategies that limit access**. Two states removed people from their ADAP after reducing financial eligibility. Some states have been forced to remove vital drugs from their ADAP formulary and/or institute annual expenditure caps and cost-sharing.

- Community is also engaged in cost-containment measures with industry, including rebates, price reductions, and patient assistance programs.

Requested Increases Authorized in Legislation

The amounts requested for FY2012 match the levels Congress authorized for the program in FY2012 in the Ryan White HIV/AIDS Treatment Extension Act of 2009.

Program Component		FY 2012 Authorization	FY 2012 Request	Estimated Need
Part A		$759.1M	$759.1M	$1,018M
Part B	**Base**	$1,489M	$495M	
	ADAP		$991.0M	
Part C		$272.2M	$272.2M	$406.8M
Part F: AETCs		$40.2M	$50M	

Part A—Cities and Communities

More than 70% of all people living with HIV/AIDS in the U.S. reside in a Part A community. Part A serves an estimated 300,000 people living with HIV/AIDS per year. **$759.1 million** in 2012 will partially address the current unmet need for medical care and some support services for uninsured and underinsured people living with HIV/AIDS in these hard-hit communities. The rising cost of care due to **health care inflation** and the **complexity of care as the population ages** are affecting the amount of services provided–the number of visits for health-related care decreased from 3.18 million visits in 2005 to 2.6 million in 2009.

Part B—AIDS Drug Assistance Program

$991 million in 2012 are needed to reduce and prevent waiting lists, formulary reductions and other cost containment measures and to allow all state ADAPs to provide the full range of antiviral medications and treatments for infections and side effects.

Part C—Community Health Centers and Clinics

Over 247,000 persons living with HIV/AIDS receive medical care in Part C–funded community health centers and clinics each year. **$272.2 million** in 2012 would allow Part C clinics to provide outpatient medical care to the 30,000+ people expected to enter care at those sites next year.

Part F—AIDS Education and Training Centers

$50 million in 2012 for AIDS Education and Training Centers would support the training of health care providers to care for growing patient caseloads and address the growing complexities of treating those with co-morbidities and drug side effects.

Funding Requests

We support the full community request for the entire Ryan White portfolio.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR COALITION

Building the Capacity of Ryan White Program Part A Service Needs: FY 2012

1,381,418—the estimated number of people living with HIV/AIDS in 2012[1]

980,807—the estimated number of people living with HIV/AIDS in Part A jurisdictions in 2012[2]

196,161—the estimated number of uninsured people living with HIV/AIDS living in a Part A jurisdiction in 2012[3]

$5,190 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 and home health care[4]

$1,018,075,590–the estimated amount needed to meet the need for outpatient medical care (excluding medications) and some related support services at Ryan White Program Part A-funded care centers in 2012 [$5,190 x 196,161]

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 2012 Justification of Estimates for Appropriations Committees*, p.256.
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.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR COALITION

Building the Capacity of Ryan White Program Part C Service Needs: FY 2012

1,381,418—estimated number of people living with HIV/AIDS in 2012[1]

247,133—number of people living with HIV/AIDS served by Part C providers in 2008[2]

⇩

79,082—estimated number of uninsured living with HIV/AIDS served by Part C in 2008[3]

⇩

168,050—estimated number underinsured living with HIV/AIDS served by Part C providers in 2008[3]

⇩

$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[4]

⇩

$277,866,082—estimated cost of providing care to uninsured people living with HIV [79,082x$3,501]

⇩

$128,894,350—est. cost of providing care to underinsured people living with HIV [168,050x$767[5]]

⇩

$406,760,432—estimated funding needed to meet demand for outpatient medical care (excluding medications) at Ryan White Program Part C care centers

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. *US Department of Health and Human Services Fiscal Year 2012 Justification of Estimates for Appropriations Committees*, p.267.
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 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.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR COALITION

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.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF

CAEAR COALITION

June 2, 2011

Mary K. Wakefield
Administrator
Health Resources and Services Administration
5600 Fishers Lane
Rockville, Maryland 20857

Dear Administrator Wakefield:

On behalf of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, I am writing to express concern regarding the implementation of the HIV/AIDS Bureau's recent release of the "Ryan White HIV/AIDS National Monitoring Standards" for Part A and Part B grantees and to reiterate the issues outlined by our colleagues at the National Alliance for State and Territorial AIDS Directors (NASTAD). We believe that the burdens created by the standards and the lack of adequate grantee involvement in the development warrant placing them on hold until they can be fully vetted and analyses of the cost and impact on grantee operations can be conducted. Representatives of CAEAR Coalition, including Part A grantees, would welcome the opportunity to discuss these matters with you.

While the National HIV/AIDS Strategy (NHAS) stresses that federal agencies should take steps to simplify grant administration activities and "streamline data collection and reporting requirements," it appears that HAB has developed and begun implementing the monitoring standards without consideration of policies and procedures that Ryan White grantees already have in place and the overall emphasis on streamlining and simplification laid out in the NHAS.

CAEAR Coalition recognizes the importance of robust sub-grantee monitoring. Part A grantees are committed to demonstrating accountability to the federal government and to the hundreds of thousands of individuals living with HIV/AIDS who they serve. Over the course of the Ryan White Program, Part A grantees have developed their own programmatic and fiscal monitoring standards. The vast majority of Ryan White grantees have not experienced serious issues with their sub-grantees and their own systems have identified and allowed grantees to address problems expeditiously. CAEAR Coalition is concerned that the new standards were developed without adequate or thorough input from Ryan White grantees, are overly burdensome, and inconsistent with several tenets of the NHAS.

HAB staff members have indicated to our colleagues that many of the monitoring standards are government-wide required federal standards. However, these standards are not required of Ryan White Part C or D grantees or by the Centers of Disease Control and Prevention (CDC) HIV-related grantees. Indeed, the approach utilized by the new standards is inconsistent with the process used by the Division of Community-Based Programs for Part C and Part D, which has a much greater focus on quality management and reports findings as legislative requirements, programmatic

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requirements and improvement opportunities. At the same time that the federal interagency work group on the NHAS is meeting to discuss streamlining federal reporting requirements and measurements, it is counterproductive to implement these standards.

Since the release of the standards, Ryan White grantees have reviewed and analyzed the standards and identified several challenges with their implementation. The following are examples of issues identified by Part A and Part B grantees.

• The details and complexity contained in the standards must not be underestimated. There are 258 pages containing over 325 standards. HRSA has noted that none of these standards are new. However, the expectations and related policies and procedures needed to implement these standards are new. This will result in significant modification for some grantees, some involving wholesale restructuring of their current, HAB-approved systems. Previous monitoring efforts have been focused on ensuring that appropriate, quality services are being delivered to clients and that positive medical outcomes are being achieved as a result of those services. Implementing these standards will force grantees to shift the focus of their monitoring activities to a more administrative, process-oriented review. There will no longer be time to assess the quality, effectiveness, and outcomes of services. The resources and time needed to complete these modifications are sizable. It is also anticipated that implementation of the standards will require a complete restructuring of grant goals and budgets. As a part of the efforts to improve the standards, HAB should develop a standardized assessment tool and report format and identify the minimum/optimal skill set required for program/contract monitors. After the standards are fully vetted and modifications made, HAB should allow grantees to submit a time-framed plan to guide phased-in implementation of the standards.

• The standards require that an annual on-site monitoring visit occur for every entity receiving Part A funds. This visit must include review of both programmatic and fiscal standards. This requirement will cause significant issues for many grantees due to the number and geographic distribution of their sub-grantees and limited funds available for administrative functions. For many grantees this would require a full site visit at least once a week, every week of the year, leaving little staff capacity for any other grant related work. Alternatives to this annual requirement should be explored, including a waiver process with a limit on the maximum number of years the requirement can be waived. Existing monitoring practices and past performance of the sub-grantee should be considered. This standard is far more stringent than HAB currently uses to monitor their Ryan White grantees.

• Ryan White Part A grantees are not expected to review every client record during a monitoring visit. However, the standards contain an expected "norm" governing the sample size for client record reviews. The sample size decreases as the total number of clients served by the agency increases. As an example, for an agency serving 50 clients or less, the "norm" is to review 100 percent of the cases. If these recommendations become a minimum expectation, the time it takes to complete a

monitoring visit will be increased substantially. Again, combined with the requirement to see every agency every year, the standards would significantly diminish staff capacity to accomplish other work. In addition, the FAQs indicate that all sub-grantee invoices should be accompanied by documentation. Many EMAs, with HAB's approval, have used on-site reviews, sampling methodologies and other approaches to audit support documentation, reserving complete monthly reviews for sub-grantees with fiscal reporting weaknesses. Requiring universal monthly documentation will be needlessly costly and onerous for sub-grantees and grantee staff.

• The FAQs also note that in the case of performance-based contracts, the grantee is required to perform an annual reconciliation of the amount charged for the service with the actual cost of delivering the service. While it is difficult to know what the standards mean without further details, this requirement appears to be inconsistent with the way performance-based contracts are managed and monitored under billing and monitoring procedures previously approved by HRSA HAB – procedures which align the delivery of high-quality services with reimbursement without compromising the EMA's monitoring of allowable Ryan White costs.

• All costs associated with monitoring sub-grantees are to be considered administrative in nature. Given the magnitude and complexity of the requirements, grantees will see an increase in costs associated with monitoring. Grantees are held to a 10 percent administrative cap on all grant related expenditures (inclusive of Planning Council costs). Including these increased costs as administrative expenditures will create cap-related issues for some grantees. For many grantees, it will be impossible to meet these standards and remain within the cap.

• Grantees are required to calculate the unit costs associated with providing services under the grant and to determine the "reasonableness" of these costs. There are many factors that must be included in an accurate calculation of unit costs, and there are many more factors that must be included in determining "reasonableness." Area economic factors, availability of services and resources, client characteristics, and disparate costs of medical care vary widely both between and within jurisdictions. These factors alone make any determination of "reasonableness" subject to interpretation and do not provide any objective analytical value. Calculation and analysis of unit costs to determine reasonableness is not a legislative requirement for Ryan White. This standard is based on new HRSA policy.

• HRSA contracted with a consultant (Comprehensive Technical Assistance Group (C-TAG)) to provide assistance in developing the monitoring standards. This same consultant recently issued an announcement offering technical assistance to grantees in implementing the standards. For a monetary fee, this consultant will provide assistance to grantees to implement the standards or conduct the monitoring as a subcontractor. That the consultant firm that developed the standards will now profit from the standards calls into question the legitimacy of the standards and the integrity of the process through which they were developed. The practice seems to violate HAB's existing policy on conflict of interest. In addition, individual consultants from C-TAG are frequently used in HAB site visits on unrelated measures.

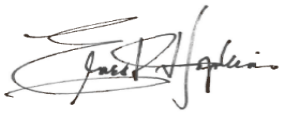
• The standards are effective April 1, but HRSA is not providing TA to grantees until July. Before the standards are implemented, grantees should have the opportunity to clearly understand HRSA's expectations for the implementation of the standards, including the HRSA/HAB monitoring process.

• The Monitoring Standards FAQ contains information that is in direct opposition to long-standing grants management technical assistance provided by HAB. For example, the FAQ states that rent and utility expenses incurred by sub-grantees are administrative costs and cannot be shown as direct service expenses. For years, some grantees with the backing of HAB grants management and OMB Circular guidance have been advising sub-grantees that rent and utility costs associated with service delivery are a direct expense, making this change a significant problem for some grantees.

These standards were not thoroughly vetted with Part A grantees; there was not a formal process by which HAB solicited input from all Part A and B grantees on the entire set of standards. Given the significant problems with the development and implementation of these standards, including the egregious conflict of interest by the developing contractor, and the standard's detrimental impact on grantee operations and service delivery, CAEAR Coalition urges HAB to suspend their implementation pending further review and revisions. As a part of this process, CAEAR Coalition urges HAB to actively engage Part A and Part B grantees and conduct an assessment of resources needed to comply with the standards, including an assessment of the impact on actual monitoring time required.

CAEAR Coalition looks forward to working with HRSA to resolve this issue. Please contact me if you have questions or would like additional information.

Sincerely,



Ernest Hopkins
Chair, Board of Directors

cc: Ron Valdiserri, Deputy Assistant Secretary for Health, Infectious Diseases, HHS
Deborah Parham Hopson, Associate Administrator for HIV/AIDS, HRSA
Barbara Aranda-Naranjo, Director of the Division of Service Systems, HRSA/HAB

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR COALITION

Health Care Reform Implementation Priorities

Essential Health Benefits Package

Federal: advocate for a definition of 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.

State and Local: urge state and local officials to weigh in with the Secretary, engage and train state Medicaid offices and key providers on new benefits, and engage state health officials to ensure that the Benchmark benefits package established for new Medicaid recipients includes the essential services needed for comprehensive HIV care.

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

Federal: advocate for inclusion of HIV and AIDS in regulations defining what qualifies as a "chronic condition" in the Medicaid Health Home Program and ensure that states are provided with appropriate guidance as to how to set up these programs.

State and Local: 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

Federal: push HRSA to encourage Community Health Centers applying for New Access Point grants to include comprehensive health and support services for people living with HIV and AIDS.

State and Local: 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.

Funding for HIV/AIDS Prevention and Wellness Initiatives

Federal: advocate for HHS to target funds to support a broad range of HIV prevention and public health services needs, including grants for community-based organizations, funding for studies and initiatives addressing stigma, and funding to shore up state HIV/AIDS budgets.

State and Local: ensure that health centers and local and state health officials are aware of federal funding opportunities.

Primary Care Workforce Training and Expansion

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 and Local: work with states and localities to encourage health professional workforce development, such as by developing and collaborating with community health worker networks, and ensure that state and local health officials, health centers, and community-based organizations are aware of new federal funding opportunities.

Temporary High Risk Pools

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 Ryan White funds to cover the premiums, copayments and deductibles of high risk pool insurance.

State and Local: push states that have opted to run their own plan to streamline the application process, such as by allowing HIV infection 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

Federal: 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 which care and service delivery systems funded by the Ryan White Program 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 and Local: encourage Ryan White providers to integrate into Medicaid and state insurance exchange provider networks by developing the infrastructure necessary to contract with state Medicaid offices and state insurance exchanges. Educate and collaborate with Ryan White grantees to ensure seamless transition to insurance expansions going into effect over the next five years.

Section 1115 Medicaid Waivers

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 and Local: encourage states to consider applying for a Section 1115 waiver.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR COALITION

Health Care Reform Checklist for AIDS Service Organizations

Organization Operations

- ☐ Explore ways to receive designation as a 330 health facility, Federally Qualified Health Center (FQHC), or FQHC "look-alike." HRSA offers health center planning grants.

- ☐ Alternatively, explore ways to formally contract with FQHCs/ 330s and other medical institutions on wrap-around and support services (linked to the Essential Benefits Package definition). The medical home model requires more community follow-up than is currently done by many medical providers.

  Some Resources
  *HRSA Health Centers Program
  [http://bphc.hrsa.gov/]

  *HRSA HIV/AIDS Bureau Webcast: "FQHC Requirements"
  [http://www.careacttarget.org/library/media/habconferences/FQHCDecember10.htm]

  *HRSA Health Center Planning Grants
  [http://www.hrsa.gov/grants/apply/assistance/planning/]

- ☐ Explore existing funding streams and how they will be changing in the context of implementation of the Affordable Care Act (ACA) or other government strategic directions. Conduct a strategic planning session or SWOT (Strength, Weaknesses, Opportunities and Threats) analysis with your board of directors.

- ☐ Review what the HIV continuum of care would look like in your community without major funding from the Ryan White Program as the primary payer for health care services (e.g., if 90% or more of your clients either transitioned to Medicaid managed care or had private health insurance through an insurance exchange).

- ☐ Review what the HIV service gaps will be with Medicaid reform/changes proposed by your state health department. Will the state maintain eligibility for services currently provided or will it cut services through cost containment measures? Will states restrict the essential benefits package in advance of the federally established package of benefits?

- ☐ Review possible overlap in your care services with prevention programs to identify economies of scale and administration through better alignment or merger of existing programs and systems.

- ☐ Educate consumers about how HIV/AIDS care programs are currently funded in the community and set up a mechanism to keep them informed of the changes over the next three years.

Funding Opportunities

- ☐ Apply for a HRSA Health Center Planning Grant if applicable.

- ☐ Sign up with www.grants.gov to get daily notifications of federal funding opportunities tailored to your preferences.

- ☐ Seek out federal workforce development grants to strengthen existing staff and bring in new staff.

- ☐ Seek out new CDC prevention grants.

Federal Implementation

- ☐ Track Affordable Care Act implementation of Medical Homes (2011) and Medicaid Expansion (2014)
    - Defining of criteria (e.g., chronic conditions definition)
    - Services included in the "Essential Benefits Package"

- ☐ Monitor timeline for the rollout of the Affordable Care Act (http://www.healthcare.gov/law/timeline or http://healthreform.kff.org/timeline.aspx).

- ☐ Monitor comparative effectiveness efforts at federal agencies, nonprofit/advisory groups, such as the Institute of Medicine, and new organizations, such as the Patient-Centered Outcomes Research Institute.

State-level Implementation

- ☐ Follow state developments and connect with the designated person/office responsible for health care reform implementation in your state.

- ☐ Understand the system/process in your state by which ADAP will be covering True Out-of-Pocket (TrOOP) Expenses incurred through the Medicare D donut hole and begin to educate your staff and clients as appropriate.

- Explore the option of state Medicaid waivers to bill for Medical Case Management or other Ryan White services if they do not already exist. (Monitor developments in Primary Care Case Management pilots); get involved in state committees to redesign the care model and financing of care to reflect the needs of people living with HIV.

- Reach out to the designated person/office responsible for implementation of the Affordable Care Act in your state, or any state-wide planning groups concerned with the needs of low-income adults. Work with them to amend the state's Medicaid provisions to provide access to Medicaid insurance for adults at 133% of the federal poverty rate sooner than the ACA requires in 2014. The benefit to the state will be greater if implemented sooner than 2014.

Federal Advocacy

- Advocate for Ryan White Program "bridge" from 2013 to full implementation of health care reform in 2014.

- Educate your legislators on HIV/AIDS and how the Ryan White Program currently works in your community.

- Educate your legislators on how Ryan White Program works with other funding streams to create the HIV continuum in your community (some gaps may be closed by ACA but new gaps may appear and you need to be the resource they go to for finding out how people living with HIV/AIDS clients are impacted).

- Advocate maintaining and increasing current Ryan White Program funding to ensure continuity of care for all uninsured and under-insured people living with HIV/AIDS.

- Advocate for continued enhancements and refinements to ACA as it is implemented in the field to improve health care access for people living with HIV.

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Revised April 20, 2011

CHAIRMAN RYAN GETS NEARLY TWO-THIRDS OF HIS HUGE BUDGET CUTS FROM PROGRAMS FOR LOWER-INCOME AMERICANS

by Robert Greenstein

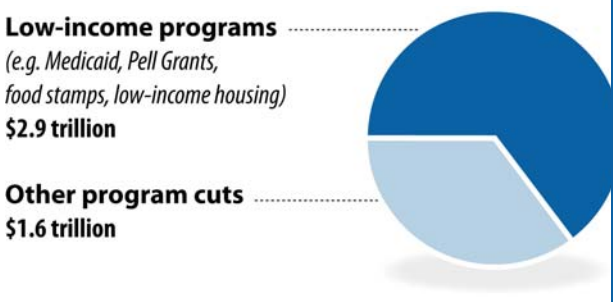
House Budget Committee Chairman Paul Ryan's budget plan would get nearly two-thirds of its $4.5 trillion in budget cuts over 10 years from programs that serve people of limited means, which violates basic principles of fairness and stands a core principle of President Obama's fiscal commission on its head.

The plan of Erskine Bowles and Alan Simpson, who co-chaired President Obama's National Commission on Fiscal Responsibility and Reform, established, as a basic principle, that deficit reduction should not increase poverty or inequality or hurt the disadvantaged. The Ryan plan, which the chairman unveiled in a news conference, speech, and *Wall Street Journal* op-ed, charts a different course, turning its biggest cannons on these people.

This finding emerges from a Center on Budget and Policy Priorities analysis of the Ryan plan. Table S-4 of the plan, as Chairman Ryan unveiled it on April 5, showed that the plan contains net program cuts of $4.3 trillion over ten years.[1] The table showed a $5.8 trillion cut in outlays from the Congressional Budget Office baseline — but $446 billion of that was interest savings and another $1.04 trillion was simply an assumption that the Iraq and Afghanistan wars will phase down on the Obama Administration's timetable. Actual program cuts produced net savings of $4.3 trillion.

Figure 1

Nearly Two-Thirds of Proposed Cuts in Ryan Plan Come from Low-Income Programs



Source: "The Path to Prosperity" FY2012 Budget Resolution

The following week, when the budget plan went to the House floor, Chairman Ryan

[1] House Committee on the Budget, "The Path to Prosperity: Restoring America's Promise," April 2011, budget.gop.gov.

added $197 billion in cuts in order to offset an overestimate of interest savings.[2] This brings the total program cuts in the plan to $4.5 trillion.

Cuts in low-income programs appear likely to account for at least $2.9 trillion — or nearly two-thirds — of this total amount. The $2.9 trillion includes the following three categories of cuts:

- **$2.17 trillion in reductions from Medicaid and related health care.** The plan shows Medicaid cuts of $771 billion, plus savings of $1.4 trillion from repealing the health reform law's Medicaid expansion and its subsidies to help low- and moderate-income people purchase health insurance.

- **$350 billion in cuts in mandatory programs serving low-income Americans (other than Medicaid).** Chairman Ryan's budget documents show that he is proposing $719 billion in cuts in mandatory programs other than Medicare, Medicaid, and Social Security, but do not specify how much will be cut from various programs (although they imply that cuts in the Food Stamp Program will be large). In this analysis, we make the conservative assumption that savings from low-income mandatory programs (other than Medicaid) would be proportionate to their share of spending in this category. Thus, we derive the $350 billion figure from the fact that about half of mandatory spending other than for Medicare, Medicaid, and Social Security goes for programs for low- and moderate-income individuals and families. This likely substantially understates the cuts that the plan would make in low-income programs. The Ryan documents show that $380 billion in cuts would come from mandatory programs in the income security portion of the budget (function 600), and the overwhelming bulk of the mandatory spending in that category goes for low-income programs. The documents also show $126 billion in mandatory cuts in the education, training, employment, and social services portion of the budget (function 500), which, based on the discussion in those documents, would likely come mainly from cuts in the mandatory portion of the Pell Grant program for low-income students.

- **$400 billion in cuts in low-income discretionary programs.** The Ryan budget documents released on April 5 showed the plan containing $1.6 trillion in cuts in non-security discretionary programs, but again did not provide details about the size of cuts to specific programs. (The documents did identify some major low-income program areas, including Pell Grants and low-income housing, as prime targets for cuts.) Here, too, we make the conservative assumption that low-income programs in this category would bear a proportionate share of the cuts. Thus, we derive the $400 billion figure from the fact that about a quarter of non-security discretionary spending goes for programs for low- and moderate-income individuals and families. (Rep. Ryan added $193 billion in cuts in non-security discretionary programs before the budget resolution went to the House floor, but Ryan said these additional cuts would come from freezing federal employees' pay and reducing the federal workforce, so we do not include them when estimating reductions in programs for low- and moderate-income households.)

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[2] Kathy Ruffing, "House Budget Committee: Mistakes Were Made," *OfftheCharts* blog, April 13, 2011, http://www.offthechartsblog.org/house-budget-committee-mistakes-were-made; House Committee on the Budget, Revised Summary Tables, updated April 11, 2011, http://budget.house.gov/UploadedFiles/SummaryTables.pdf.

Our numerical assumptions are conservative in another way, as well. When faced with the choice of which specific programs to cut, policymakers are unlikely to cut much from a number of *non*-low-income programs in these budget categories that are popular, such as veterans' disability compensation and the FBI. That means that other programs — including low-income programs — would have to be cut by more than their proportionate share.

Health Law and Policy Clinic of
Harvard Law School

June 6, 2011—For Immediate Release

Contact: Amy Killelea (617-390-2568)

AIDS Advocates Praise Obama Administration for New Initiative Promoting Access to HIV Care

Washington, DC—As part of its pledge under the National HIV/AIDS Strategy, the Centers for Medicare and Medicaid Services (CMS) released guidance and an application template today to make it easier for states to apply for Section 1115 Medicaid waivers to cover pre-disabled people living with HIV. Right now (and until 2014 when health care reform expands Medicaid to most people up to 133% of the federal poverty level), most people living with HIV have to wait until they are disabled by AIDS to be eligible for Medicaid. An 1115 waiver gives a state flexibility to immediately cover pre-disabled people living with HIV under its Medicaid program.

"This is a huge victory for the HIV/AIDS community," said Robert Greenwald, Clinical Professor of Law at Harvard Law School and Director of the school's Center for Health Law and Policy Innovation. "Early access to HIV care and treatment will save lives and is very cost-effective." And, as the recent fining from the National Institutes of Health trial (HPTN 052) study demonstrated, early diagnosis with access to care and treatment not only improves individual health, it greatly reduces transmission risk."

"We are very pleased with the commitment and leadership that CMS has shown to the National HIV/AIDS Strategy and to stemming the tide of the HIV epidemic," said David Ernesto Munar, a leading organizer of the Coalition for a National AIDS Strategy and President/CEO of AIDS Foundation of Chicago. "We know that it will not be an easy lift for states to expand access to Medicaid given the current state of the economy. But we also know that failing to implement an HIV waiver means that millions of state tax dollars will continue to go toward preventable and high-cost medical interventions. We will be working hard to encourage state Medicaid programs to review the new application process and make informed decisions about HIV-related Medicaid expansion."

A waiver will also give states an important tool in addressing the current AIDS Drug Assistance Program (ADAP) crisis. Advocates in Louisiana, for instance, hope that the state will use the waiver to move nearly 700 people currently unable to access ADAP because of the program's capped enrollment, into Medicaid. Enrique Moresco, Chair of the Louisiana AIDS Advocacy Network, has been urging the state to apply for a waiver. "We started advocating for the 1115 waiver through the State Healthcare Access Research Project (SHARP) report, which we presented to the state legislature in March, and we will be introducing a resolution committing Louisiana to study the issue," Moresco said. "Louisiana has some of the highest infection rates in the country, and by expanding Medicaid coverage through a waiver, we could be assisting many more people infected with HIV," he said. "I hope that with this guidance from CMS, the state legislature and the Medicaid office will commit to making it happen."

Now that there is concrete guidance and support from CMS, HIV health and social services providers say they will work closely with state Medicaid offices to take the necessary steps to apply for the HIV waiver.

The CMS State Medicaid Director Letter can be found at https://www.cms.gov.SMDL/SMD/. For more information about the waiver application process, visit www.taepusa.org, www.nationalaidsstrategy.org, and www.doseofchange.org.

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How to Use an 1115 Medicaid Waiver as a Bridge to 2014 for People Living with HIV and AIDS

November 2010

What is an 1115 waiver?

An 1115 waiver gives a state flexibility to expand its Medicaid program. The waiver is particularly important for the HIV/AIDS community because of the cruel "catch 22" of current Medicaid law, which requires people living with HIV to wait until they are disabled by AIDS to qualify for Medicaid. Health care reform eliminates this "catch 22" when, starting in 2014, most people with income at or below 133% of the federal poverty level will be eligible for the program. While this is great news for the HIV/AIDS community, there are still four years until the Medicaid expansion, and people living with HIV cannot wait until 2014 to access lifesaving care and treatment. An 1115 waiver will allow a state to provide a bridge to 2014 and immediately cover pre-disabled people living with HIV under its Medicaid program. The Secretary of Health and Human Services has the authority to approve a Medicaid waiver if a state meets the 1115 application requirements, the most important of which is to show that the expansion is budget neutral (i.e., federal costs with the expansion will be no more than federal costs without the expansion).

How will an 1115 waiver help my state build a cost-effective bridge to 2014?

Maximize effectiveness of state dollars by leveraging federal funds

- There are currently thousands of people on ADAP waiting lists around the country and 31 states have imposed cost saving measures such as reduced formularies. States are facing tough decisions about how to allocate scarce resources. An 1115 waiver would allow states to maximize state dollars spent to address the HIV access to care and public health crisis by leveraging federal matching funds.

North Carolina

State Response	**1115 State/Federal Response**
$14 million allocated out of fiscal year 2011 state budget to address ADAP crisis	$14 million from state would leverage $25.6 million in federal matching funds (at 64.71% FMAP) with an 1115 waiver

Alabama

State Response	**1115 State/Federal Response**
$5 million allocated out of fiscal year 2011 state budget to address ADAP crisis	$5 million from state would leverage $11 million in federal matching funds (at 68.54% FMAP) with an 1115 waiver

Provide cost-effective, "budget neutral" early intervention

- Early intervention and immediate linkage to care for people diagnosed with HIV will help defray far more costly late intervention by:
  - Reducing costly hospitalizations and other costs associated with disease progression
  - Reducing transmission rates/ community viral load
  - Reducing expenditures by disproportionate share hospitals
  - Reducing Social Security disability costs
  - Increasing productivity and employment

Allow states to implement the Medicaid expansion (mandatory in 2014) incrementally

- In 2014, every state will be required to expand Medicaid to most people up to 133% of the federal poverty level. There is a provision in the health care reform law, however, that allows states to expand Medicaid immediately. The 1115 waiver option for pre-disabled people living with HIV essentially allows states to opt for early Medicaid expansion, but for only a segment of the population. This will not only allow states to realize the cost-effectiveness benefits of early intervention immediately, but will also provide states the opportunity to test run Medicaid expansion incrementally.

What is CMS doing to support states that want to apply for 1115 waivers?

The Federal Implementation Plan for the National HIV/AIDS Strategy 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"*

The HIV/AIDS community is asking CMS to:

- Appoint a Senior Advisor on HIV to the CMS Administrator or the Medicaid Director to Coordinate NHAS Implementation;
- Appoint a Designated CMS Representative to provide technical assistance to states;
- Send a letter to state officials including state Medicaid directors and AIDS directors alerting states of the option and offering guidance as to what steps they need to take;
- Promote the waiver option on the CMS Website; and
- Organize a conference call for state officials including state Medicaid directors and AIDS directors to discuss the waiver option.
- Provide guidance to states to help them demonstrate budget neutrality.

What Can I do to Support the 1115 Waiver Option?

At the federal level:

- Ensure that the federal government fulfills its obligation under the NHAS.
  - Send letter to HHS Secretary Sebelius and CMS and White House officials, urging them to quickly act to make the waiver option a possibility for states.
  - Emphasize the message that federal support behind the 1115 waiver is crucial in addressing the current health care access and public health crisis.

At the state level:

- Let your state Medicaid officials; AIDS directors; and governors know about the 1115 waiver.
- Provide state officials with your state's story:
  - What does the access to care crisis for people with HIV look like in your state?
  - What has your state done to address the ADAP crisis?

Stay Tuned:

- Check back in with AIDS Foundation of Chicago and Treatment Access Expansion Project for a follow-up webinar on the next steps to making the 1115 waiver an option in your state.

For more information please contact:
AIDS Foundation of Chicago, http://aidschicago.org
Treatment Access Expansion Project, http://www.taepusa.org

Dear:
State Medicaid Director
State AIDS Director
State legislators

To address the HIV access to care crisis, I urge you to consider applying for a Medicaid 1115 waiver to cover pre-disabled people living with HIV.

As part of the National HIV/AIDS Strategy, the Centers for Medicare and Medicaid Services (CMS) has pledged 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." As part of this pledge, CMS has recently released guidance and an application template for states interested in pursuing a waiver. It is now up to states to make use of these tools.

Currently, there is an unprecedented access to care crisis – and public health emergency – for low-income people living with HIV. To date, AIDS Drug Assistance Programs (ADAPs) are facing severe funding shortfalls, and there are thousands of people on ADAP waiting lists across the country. These numbers continue to grow each month. Not only does this situation present a threat to individual health, but it also severely undermines the public health benefits of early treatment and prevention.

Though the health care reform law largely eliminates the Medicaid 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 people living with HIV simply cannot wait until the Medicaid expansion goes into effect in 2014 to gain access to lifesaving care and treatment. Early expansion of Medicaid coverage for this population prior to 2014 through use of an 1115 waiver will help the state to combat the access to care crisis now. Moreover, it will allow the state to provide early, cost-effective intervention to maintain the health of a population the state has to cover in 2014.

I urge you to consider using an 1115 waiver to address the current access to care crisis for people living with HIV in our state.

Sincerely,

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-26-12
Baltimore, Maryland 21244-1850

Center for Medicaid, CHIP and Survey & Certification

SMDL # 11-005

June 6, 2011

Re: Coverage and Service Design Opportunities for Individuals Living with HIV

Dear State Medicaid Director:

The purpose of this letter is to inform States of the opportunities available to provide Medicaid coverage to individuals living with HIV in support of President Obama's National HIV/AIDS Strategy (the Strategy).

This guidance informs States on how to apply for opportunities in the Medicaid program that allow for flexibility to improve care and care coordination and offer options to treat individuals living with HIV (including individuals living with AIDS, which refers to individuals living with an advanced stage of the HIV disease) in the community. Through the Medicaid program, there are numerous opportunities available for States. These coverage and service design opportunities may assist States in increasing access to care for individuals living with HIV, provide alternatives that could alleviate the current burden to AIDS Drug Assistance Programs (ADAP), and help States make progress towards implementing the expansion of Medicaid required in the Patient Protection and Affordable Care Act of 2010, as amended by the Health Care and Education Reconciliation Act of 2010 (collectively referred to as the Affordable Care Act). States may choose or apply for one or more options to extend coverage to individuals living with HIV:

1. Community First Choice;
2. Health Home for Enrollees with Chronic Conditions;
3. Section 1915(c) Home and Community Based Services (HCBS) Waiver;
4. Section 1915(i) State plan option;
5. The Money Follows the Person (MFP) Rebalancing Demonstration; and
6. Section 1115 Demonstrations.

In addition, this letter provides guidance to States who wish to submit applications for section 1115 demonstrations to cover individuals living with HIV who are not otherwise eligible for Medicaid.

Background

The United States is experiencing a domestic HIV epidemic that demands a renewed commitment, increased public attention and leadership. More than 56,000 people become infected with HIV in the U.S. each year, and there are more than 1.1 million Americans with HIV. The epidemic has claimed the lives of nearly 600,000 Americans, and affects many

more, including families and friends of those with the disease.[1] Of those living with HIV, it is estimated that less than 17 percent have private health insurance and nearly 30 percent do not have any medical coverage. [2]

In response to this domestic epidemic, President Obama released the National HIV/AIDS Strategy, which aims to achieve three primary goals: 1) reduce HIV incidence; 2) increase access to care and optimize health outcomes; and 3) reduce HIV-related health disparities. In order to achieve the goal of increasing access to care and improving health outcomes for individuals living with HIV, the Strategy encourages Federal and private partners to take the following steps to improve service delivery for individuals living with HIV:

1. Establish a seamless system to immediately link individuals to continuous and coordinated quality care when they are diagnosed with HIV.

2. Take deliberate steps to increase the number and diversity of available providers of clinical care and related services for individuals living with HIV.

3. Support individuals living with HIV with co-occurring health conditions, and those who have challenges meeting their basic needs.

Please visit: http://www.whitehouse.gov/administration/eop/onap/nhas to learn more about the Strategy.

As part of the Strategy's Federal Implementation Plan, the Centers for Medicare & Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA) are tasked with initiating a dialogue on ways to support Medicaid and Medicare providers in order to engage vulnerable populations in HIV care. To that end, CMS and HRSA strongly encourage Medicaid Directors to consult with and consider input from State Primary Care Association (PCA) Directors (http://www.bphc.hrsa.gov/technicalassistance/partner%20links/associations.html) and State AIDS Directors (http://www.nastad.org/about/res_state_Directory.aspx) to ensure that issues and concerns facing HRSA's Ryan White HIV/AIDS Programs and the federally-qualified health centers (FQHC) are addressed, since these providers are highly impacted by Medicaid policy. We are also asking States to consider how demonstration projects could be designed to improve access to HIV testing, care, and treatment for individuals living with HIV and individuals at risk for HIV infection. Please note that, in addition to the Web sites listed above, a list of PCA and State AIDS Director contacts can be obtained by emailing HIVandAIDS@cms.hhs.gov. States can reach out to these stakeholders as waiver considerations are being explored.

Medicaid is a major source of coverage for individuals living with HIV. Before the Affordable Care Act, most individuals living with HIV were ineligible for Medicaid unless they had very low incomes, or were deemed permanently disabled, due to an AIDS diagnosis. Starting in 2014, section 2001 of the Affordable Care Act expands coverage to individuals with income

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[1] Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report. 2007; 19:7 Available at http://www.cdc.gov/hiv/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf

[2] http://www.aids.gov/federal-resources/policies/health-care-reform/

under 133 percent of the Federal poverty level (FPL) and States have had the option to begin providing medical assistance to individuals eligible under this new expansion as of April 1, 2010.

Under the law, for the first time since the Medicaid program was established, States can receive Federal Medicaid payments under their State Medicaid plans to provide coverage for the lowest income adults in their States, without regard to disability, parental status, or most other categorical limitations. For more information regarding this option for coverage of individuals under Medicaid, please visit http://www.cms.gov/smdl/downloads/SMD10005.PDF. The Affordable Care Act also includes a variety of options for States to offer services to help those who need long-term services and supports at home and in the community.

Summaries of Medicaid service design and coverage opportunities that are available are outlined below.

1. Community First Choice

Section 2401 of the Affordable Care Act creates a new State Plan option to provide home and community-based attendant services and supports (Community First Choice Option) through section 1915(k)of the Social Security Act (the Act). This provision will be effective October 1, 2011. Community First Choice utilizes a person-centered plan, and allows for the provision of services to be self-directed under either an agency-provider model or a traditional self-directed model with a service budget. States can make available home and community-based attendant services and supports to assist in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing. Community First Choice also allows for transition costs (such as security deposits for an apartment or utilities) and the purchase of bedding, basic kitchen supplies, and other necessities required for transition from an institution. In addition, Community First Choice allows for the provision of services that increase independence or substitute for human assistance to the extent that expenditures would have been made for the human assistance, such as non-medical transportation services. This option also allows for the purchase of back-up systems or mechanisms (such as the use of beepers or other electronic devices) to ensure continuity of services and supports. States that elect to provide the Community First Choice option will receive an increase of 6 percent in their Federal Medical Assistance Percentage (FMAP) for the provision of these services. For more information about Community First Choice, CMS has released a proposed rule. Please visit http://www.gpo.gov/fdsys/pkg/FR-2011-02-25/pdf/2011-3946.pdf for more information.

2. Health Home for Enrollees with Chronic Conditions

Section 2703 of the Affordable Care Act (Health Home for Enrollees with Chronic Conditions) offers a new Medicaid State Plan option to provide coordinated care to individuals with chronic conditions, which may include individuals living with HIV. As mentioned in the State Medicaid Director letter on health homes, issued on November 16, 2010, section 1945(h)(2) of the Act authorizes the Secretary to expand the list of chronic conditions reflected in this provision and the Secretary will consider HIV/AIDS for incorporation into health home models. Since individuals with HIV may also be experiencing mental health and/or substance use issues, this provision offers important coordinated care opportunities for supporting physical and behavioral

health, as well as linkages to long-term supports, which are fundamental elements of a successful health home.

However, a State cannot offer a health home to an individual solely on the basis of having an HIV diagnosis. Per statutory requirement, the individual must have two or more chronic conditions (as defined by the State and approved by CMS), or have one chronic condition and be at risk of another. If you have any questions about health homes, please refer to the State Medicaid Director letter at http://www.cms.gov/smdl/downloads/SMD10024.pdf. You may also send any questions about health homes to the CMS health homes mailbox at healthhomes@cms.hhs.gov.

3. HIV Initiatives under Section 1915(c) HCBS Waivers

Under section 1915(c) of the Act, States may design HCBS waiver programs. The section 1915(c) HCBS waiver program is the predominant Medicaid program for providing long-term services and supports in the community (non-institutional settings) as an alternative to an institutional setting, such as a hospital or nursing home.

The section 1915(c) HCBS waiver program is used by a number of States to serve individuals with HIV in the community. States may use additional targeting criteria to specifically design a waiver to serve individuals with HIV or they may define a broader target group into which individuals with HIV would be included. Thirteen States currently operate stand alone section 1915(c) waivers for individuals with HIV. Many others successfully serve individuals with HIV in their more broadly targeted waivers, which often offer a rich service package that can address diverse service needs.

States offer a wide range of services under the section 1915(c) waivers, including those targeted solely for individuals with HIV. Examples of services that States currently offer in section 1915(c) HIV waivers include: Case Management, Attendant Care, Home Health, Specialized Medical Equipment and Supplies, Nutritional Consultation, Respite, Environmental Modifications and Supplies, Private Duty Nursing, Personal Care, Home Maker Services, Personal Assistance, and Home Delivered Meals. To learn more about HCBS waivers or to submit an application on-line please visit https://www.hcbswaivers.net/CMS/faces/portal.jsp.

4. HIV Initiatives under Section 1915(i) State Plan Home and Community-Based Services

Section 1915(i) of the Act (HCBS as a State Plan option) offers an unprecedented opportunity to serve individuals with HIV. Section 1915(i) was modified through section 2402 of the Affordable Care Act with changes that became effective October 1, 2010. CMS released a State Medicaid Director letter (http://www.cms.gov/smdl/downloads/SMD10015.pdf) on August 6, 2010, discussing the changes to section 1915(i) of the Act, including expanded eligibility criteria, the ability for States to target the benefit to certain populations, and an expanded array of services. HCBS can be an essential component of an individual's health care continuum, and can work to support and bolster clinical interventions. Five States currently have approved section 1915(i) HCBS in their State plans.

This option provides more flexibility than the section 1915(c) HCBS waivers because it includes less restrictive cost neutrality and institutional level of care requirements, allowing States to provide HCBS to prevent or delay the need for institutional care. The services that the States may offer now under the section 1915(i) benefit are the same as those available under section 1915(c) of the Act, and can include personal care, nutritional counseling, anticipatory grief and bereavement counseling, nursing and other specialized supports that can be effectively tailored to meet the needs of an individual with HIV.

5. The Money Follows the Person Rebalancing Demonstration Program

The Money Follows the Person (MFP) Rebalancing Demonstration Program was authorized by Congress in section 6071 of the Deficit Reduction Act of 2005, and was designed to provide assistance to States to balance their long-term care systems and to help Medicaid beneficiaries transition from institutions to the community. Congress initially authorized up to $1.75 billion in Federal funds through fiscal year (FY) 2011 to:

1. Increase the use of HCBS, and reduce the use of institutionally-based services;

2. Eliminate barriers and mechanisms in State law, State Medicaid plans, or State budgets that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive long-term care in the settings of their choice;

3. Strengthen the ability of Medicaid programs to ensure continued provision of HCBS to those individuals who choose to transition from institutions; and

4. Ensure that procedures are in place to provide quality assurance and continuous quality improvement of HCBS.

Section 2403 of the Affordable Care Act extended the MFP Demonstration Program for an additional 5 years through 2016, and appropriates an additional $450 million for each fiscal year 2012 through 2016, totaling an additional $2.25 billion in Federal funds. Funds awarded in 2016 are available to States for expenditures until fiscal year 2020. The extension of the MFP Demonstration Program offers States substantial resources and additional program flexibilities to remove barriers and improve an individual's access to community supports and independent living arrangements.

MFP grantees may amend their Operational Protocols at any time during the demonstration to include individuals living with HIV as a target population for transition from qualified institutions to community-based settings. For an individual's first 365 days in the community, MFP grantees may also include additional demonstration and supplemental services that can address the special needs of an individual with HIV. For more information on the MFP Rebalancing Demonstration, please visit: http://www.cms.gov/DeficitReductionAct/20_MFP.asp

6. Section 1115 Demonstrations

Section 1115 of the Act allows the Secretary of Health and Human Services (the Secretary) to waive certain provisions of title XIX of the Act for experimental, pilot, or demonstration projects

(demonstrations). When the Secretary finds that the demonstration project is likely to assist in promoting the objectives of Medicaid, section 1115 also provides for Federal Financial Participation (FFP) for demonstration costs which would not otherwise be considered as expenditures under the Medicaid State plan.

An HIV section 1115 demonstration will allow States the flexibility to expand access to individuals with HIV and allow such individuals to become eligible for services through a demonstration, without having to be permanently disabled due to an AIDS diagnosis. In addition, providing these services will help promote health and better health outcomes among individuals with HIV, helping them to lead healthier and longer lives. The demonstration may be designed to provide more effective, early treatment of HIV by making available a limited or comprehensive package of services, which may include anti-retroviral therapies or case management to ensure treatment adherence. Early treatment and case management services provided to individuals with HIV create efficiencies in the Medicaid program enabling the extension of coverage to individuals who would otherwise be without health insurance.

Features of Existing Section 1115 HIV Demonstrations

CMS has previously approved two section 1115 HIV demonstrations for the District of Columbia and Maine. The District of Columbia's HIV demonstration provided full Medicaid benefits to uninsured District residents who are HIV positive, and whose incomes are at or below 100 percent of the FPL. The goal of the demonstration was to provide more effective, early treatment of HIV utilizing discount drug pricing. Through the Department of Defense drug pricing, only available to the District, and a limited pharmacy network, the District was able to provide anti-retroviral prescription drugs to demonstration enrollees at a significantly lower price. One of the key features of the District's Demonstration was that intake for the program was conducted by the HIV/AIDS Administration case managers, allowing individuals with HIV to be linked to all HIV programs available to them in the District.

The Maine HIV Demonstration applies rigorous care protocols, along with case management, to disabled Medicaid recipients under 100 percent of the FPL with the goal of delaying the onset of full-blown AIDS, and using those savings to expand coverage to uninsured low-income individuals living with HIV who are at or below 250 percent of the FPL. The expanded coverage provides a comprehensive benefit package, including anti-retroviral therapies to individuals not otherwise eligible for Medicaid, but who are HIV positive.

Budget Neutrality for Section 1115 Demonstrations

In addition to serving the purposes of the Medicaid program and improving care for low-income individuals, demonstrations must be budget-neutral. This means that the proposed demonstration cannot cost the Federal government more than it would absent the demonstration. In order to meet budget neutrality, CMS and the State establish a budget ceiling based on five years of historic State specific expenditure data for each individual population the State is going to cover under the demonstration. This initial amount is then trended forward based on a negotiated trend rate for the approved demonstration period. Administrative costs are not included in the budget neutrality limit, but the State must separately track and report additional administrative costs that are directly attributable to the demonstration. When developing the budget neutrality models, the initial set of data that States should try to obtain are the historic enrollment and budgetary

data by eligibility category, then project future enrollment and per member per month costs of coverage for populations that would be covered in the waiver. CMS has available data on HIV spending by State that States may use to facilitate the construction of budget neutrality. These data can be obtained by contacting Mr. Richard Jensen (contact information included near end of letter).

CMS will work with States to develop a streamlined and flexible approach to budget neutrality for these waivers. We encourage States interested in applying for an 1115 demonstration to contact CMS to identify the most appropriate and efficient budget neutrality methodology for each State.

Submission Process for Section 1115 Demonstrations

To assist States in applying for section 1115 demonstrations to cover individuals with HIV, CMS has developed a draft application template for consideration. Please review the instructions at the beginning and throughout the template for the portions that require the State to input information. CMS hopes that this information is helpful to States for successful submission of a section 1115 demonstration.

CMS must review and approve the request before it will be considered complete, even when a State uses the draft template. For the purpose of initiating the Federal review process, States must provide the information listed below:

- A demonstration program description, and goals and objectives that will be implemented under the demonstration project.
- The description of the proposed health care delivery system, eligibility requirements, benefit coverage, and cost sharing (for example, premiums, copayments, and deductibles) required of individuals that will be impacted by the demonstration.
- An estimate of the expected increase or decrease in annual aggregate expenditures by population group impacted by the demonstration. If available, include historic data for these populations.
- An estimate of historic coverage and enrollment data (as appropriate), and estimated projections expected over the term of the demonstration, for each category of beneficiary whose health care coverage is impacted by the demonstration. For example, States may choose to have a certain benefit set for enrollees at or below a certain FPL and a different benefit package for those above that certain FPL.
- Other demonstration program features that require the State to deviate from the provisions of the Medicaid and CHIP programs.
- The types of waivers and expenditure authorities that the State believes to be necessary to authorize the demonstration.
- The research hypothesis or hypotheses that are related to the demonstration's proposed changes, goals, and objectives, a plan for testing the hypotheses in the context of an evaluation, and, if a quantitative evaluation design is feasible, the identification of appropriate evaluation indicators.
- CMS recommends that States seek consultation with the State Substance Abuse Authority, State Mental Health Authority, and other State Agencies that fund or oversee HIV treatment during the development of their HIV demonstration proposal.

Additionally, States must comply with the State Notice Procedures set forth in 59 Fed. Reg. 49249 (September 27, 1994), and the tribal consultation requirements pursuant to section 1902(a)(73) of the Act as amended by section 5006(e) of the American Recovery and Reinvestment Act of 2009. In States with Federally recognized Indian tribes, Indian health programs, and/or Urban Indian organizations, the State is required to submit evidence to CMS regarding the solicitation of advice from these entities prior to submission of any demonstration proposal.

Lastly, section 1115 demonstration applications may be submitted electronically to HIVandAIDS@cms.hhs.gov or by mail to:

Mr. Richard Jensen
Centers for Medicare & Medicaid Services
Children and Adults Health Programs Group
Mail Stop: S2-1-16
7500 Security Boulevard
Baltimore, MD 21244

We hope this information will be helpful. CMS is available to provide technical assistance to States regarding special Medicaid programs for HIV. Questions regarding this guidance may be directed to Ms. Barbara Edwards, Director, Disabled and Elderly Health Program Group, or Ms. Vikki Wachino, Director, Children and Adults Health Program Group at (410) 786-5647. We look forward to our continuing our work together.

Sincerely,

/s/

Cindy Mann
Director

Enclosure