

# Essential Components of Effective HIV Care: A Policy Paper of the HIV Medicine Association of the Infectious Diseases Society of America and the Ryan White Medical Providers Coalition

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**Human immunodeficiency virus (HIV) antiretroviral agents and effective HIV care management transformed HIV disease from a death sentence to a chronic condition for many in the United States. A comprehensive HIV care model was developed to meet the complex needs of HIV patients, with support from the Ryan White program, the Veterans Administration, and others. This paper identifies the essential components of an effective HIV care model. As access to health care expands under the National HIV/AIDS Strategy and the Patient Protection and Affordable Care Act, it will be critical to build upon the HIV care model to realize positive health outcomes for people with HIV infection.**

## THE EVOLUTION OF HIV CARE

Antiretroviral therapy and expert human immunodeficiency virus (HIV) care management transformed HIV disease from a death sentence to a chronic condition for many in the United States, as evidenced by the near-normal life spans expected for most HIV patients today [1]. The complexity of treatment and management of this multiorgan system disease requires coordination among many providers in outpatient and inpatient settings. The comprehensive HIV care model was developed to address the challenges providers face

in meeting the complex medical and psychosocial needs of many HIV-infected patients [2]. The model has been critical to the success of HIV treatment in dramatically reducing HIV morbidity and mortality rates by as much as 80% [3]. In the HIV Prevention Trials Network 052 study, antiretroviral therapy was associated with a 96% reduction in sexual transmission to HIV-negative partners and with improved health outcomes for the HIV-infected patient. In light of these results, we anticipate an even greater emphasis on identifying and linking people with HIV to care, which will require greater system capacity and increased emphasis on effective HIV care models [4].

The Ryan White program is one example of an effective HIV care model. Created by the US Congress in 1990 to help communities respond to the HIV epidemic, the program grants HIV clinics the flexibility to develop systems of care that are responsive to the needs of local patient populations [5]. The program is the third largest funder of HIV care in the United States, after Medicare and Medicaid, and provides grants to states, high-impact

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cities, and clinical programs [6]. It has supported the development of centers of excellence in HIV care across the United States.

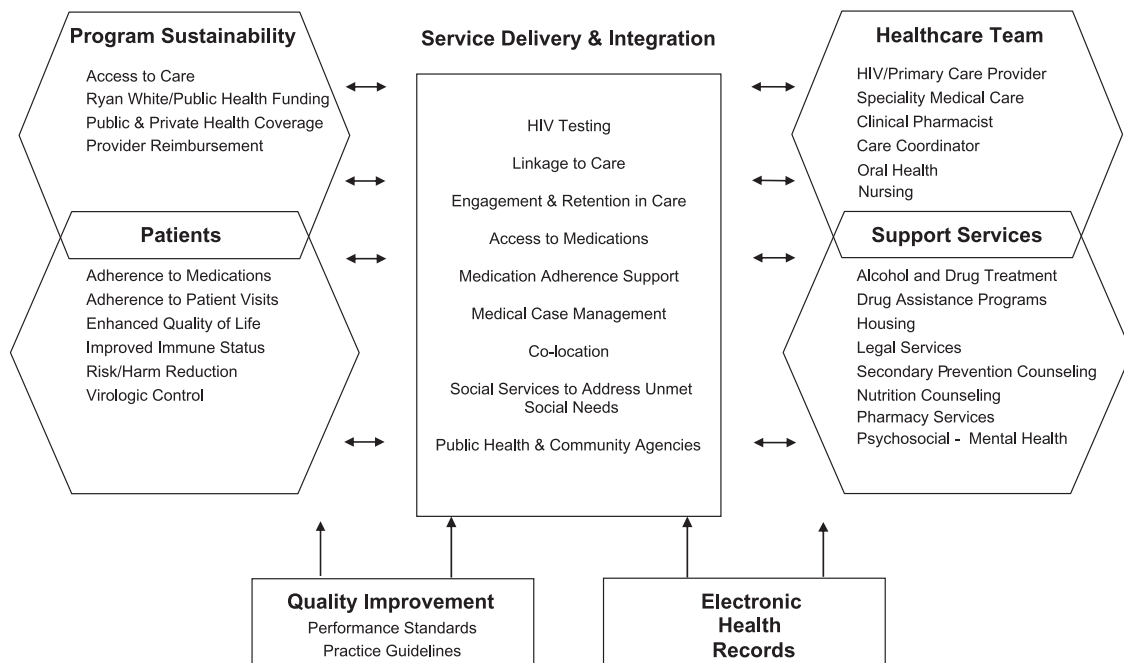
The president’s National HIV/AIDS Strategy (NHAS) sets a framework for leveraging federal and private resources to reduce HIV incidence, increase access to care, improve health outcomes, and reduce HIV-related disparities [7]. The Patient Protection and Affordable Care Act (ACA) together with the NHAS provides an unprecedented opportunity to improve access to HIV care and develop more sustainable funding streams that can be used to expand access to the effective HIV care model developed by the Ryan White program [8, 9]. To do so will require Medicaid, Medicare, and private insurers to adopt delivery systems and risk-adjusted payment mechanisms that support access to effective HIV care. This paper outlines the essential components of an effective HIV care model (Figure). It will be critical to build on this effective model for chronic disease management to promote positive health outcomes for people with HIV infection, particularly those with more intense medical and social service needs, as they gain health insurance coverage under the ACA.

## GOALS OF HIV CARE

Effective HIV care leads to earlier and greater engagement in care, effective viral control, improved immune status, near-normal life expectancy, enhanced quality of life, and prevention of HIV transmission [4, 10]. These goals can be achieved through

increased HIV testing within communities, efficient linkage to HIV primary continuity care and specialty care, access to HIV medications, medication adherence support, efforts to retain patients in care, and social services that address the unmet psychosocial needs of HIV-infected patients [11, 12]. However, if these essential aspects of effective care are fragmented, that is, not integrated, patients receive either incomplete care or no care at all. The NHAS estimates that 35% of patients newly diagnosed with HIV are not linked to HIV care within 3 months of diagnosis, which is recommended by the Centers for Disease Control and Prevention. However, higher levels of linkage are found in integrated care systems [7, 13]. Previous reports estimated that between 30% and 50% of HIV patients are not in ongoing care and do not have reliable access to HIV treatment. Ryan White clinical programs report that 73% of patients are in continuous care, defined as at least 2 visits, 3 months apart, within 1 year [7, 14–16]. Stigma and health disparities also lead to inconsistent care [1, 17]. Delayed entry into care and cycling in and out of care can lead to poor clinical outcomes, development of drug-resistant virus, and transmission of HIV to others [18].

As the goals of HIV care suggest, integrated medical care for HIV-infected patients is essential. In general, this has been achieved through the “medical home” model. In this model, access to primary and specialty care is coordinated and monitored by the HIV primary care team, as are psychosocial and social services for patients based on their needs. HIV providers have subscribed to this model of care since the early 1990s, with



**Figure.** Essential components of HIV care. Abbreviation: HIV, human immunodeficiency virus.

Ryan White Part C clinics, Veterans Administration (VA), and other health care systems as strong examples [19–21]. The high rates of care and treatment adherence required for ongoing suppression of HIV are best supported within this type of integrated service delivery environments, such as Ryan White–funded clinics and the VA [22]. This is particularly true for patients with 2 or more co-occurring conditions.

The extent and type of care integration vary according to the complexity and needs of a clinic’s HIV patient population. The simplest category of collaborative services is coordinated care that is delivered in different settings but with information sharing among the programs. Colocated (services delivered at one location, with data sharing) and integrated (merged medical and behavioral health care components, including mental health and substance use treatment in one treatment plan) medical services are used for patients with complex needs to prevent barriers or gaps in service delivery. Electronic health records (EHRs) that can be shared by the entire care team, specialists, and others who provide the patient’s care are a key component of the integrated care model.

Lower levels of integration can be sufficient for the care of some HIV patients. Critical system components for all levels of integration include established relationships with providers and ongoing communication between the HIV primary care team or the HIV expert and other specialty, primary care, mental, and social service providers. Effective HIV programs allow for a tailored approach for a service population and an individualized approach for patients, using a variety of methods to meet a broad range of needs.

## **ELEMENTS OF CARE DELIVERY**

### **Care Team**

The HIV care team includes an HIV expert who manages or co-manages the patient’s HIV primary continuity care needs and identifies subspecialty care needs. A care coordinator, who may be a qualified nurse, case manager, or another member of the care team, is responsible for maintaining communication and coordination with other providers as well as identifying and coordinating access to services such as psychosocial support, reproductive and gynecologic services, alcohol or drug treatment, drug assistance programs, prevention counseling, and other services required to meet basic needs. Medication management is a critical component of primary HIV care, and ideally a clinical pharmacist with HIV expertise is included on the team to identify drug interactions, support patient adherence and medication management, and oversee medication profiles for patients who see multiple medical providers [23–26].

A range of other specialists also participate on the HIV care team to treat the comorbidities common among HIV patients, such as hepatitis B and C, HIV-related and nonrelated

malignancies, heart disease, metabolic disorders, serious mental illnesses, and substance use disorders, and to meet needs of unique populations, such as women requiring obstetric-gynecological care [27–32]. Subspecialists ideally have an ongoing relationship with the HIV care team and have the appropriate level of comfort and expertise with HIV disease. Mental health and substance use treatment services, including psychiatric care and psychotherapy, are particularly important given that as many as 50% of HIV patients also have a psychiatric diagnosis and/or a substance use disorder [33]. Dental and oral health care is recognized as an important component of comprehensive HIV care, and access to oral health providers with HIV experience is preferred [34].

### **HIV Medical Provider Expertise**

Patients with HIV disease who are managed by clinicians with greater HIV experience and expertise have better health outcomes and receive more appropriate and cost-effective care, regardless of the clinician’s specialty training [35–38]. HIV disease does not fall under the purview of any one medical specialty—physicians trained in internal medicine, family medicine, and other medical subspecialties join infectious disease specialists as HIV experts. Although many HIV experts are infectious disease physicians, not all infectious disease physicians are HIV experts. Ongoing patient management and continuing education are required for HIV expertise, regardless of specialty training.

The primary care and specialty boards do not recognize an HIV specialty designation. The HIV Medicine Association (HIVMA) developed guidance in 2002, updated in 2010, to assist third-party payers, health systems, and institutions in identifying HIV physicians who are qualified to provide HIV care. HIVMA recommends a combination of patient management experience and continuing medical education to identify qualified HIV physicians. (HIVMA recommends that HIV physicians have managed a minimum of 25 patients with HIV during the previous 36 months and have completed a minimum of 40 hours of category 1 HIV-related continuing medical education during the same period. HIVMA also recommends that infectious disease physicians certified or recertified within the previous 12 months be considered qualified HIV physicians. In the 36 months immediately following certification, newly certified infectious diseases fellows should be managing a minimum of 25 patients with HIV and earning a minimum of 10 hours of category 1 HIV-related continuing medical education per year.) The American Academy of HIV Medicine (AAHIVM) has a credentialing process for HIV physicians, nurse practitioners, physician’s assistants, and pharmacists. The Association of Nurses in AIDS Care created the HIV/AIDS Nursing Certification Board for certification of registered nurses and nurse practitioners in HIV nursing [39]. Some states, including

California, have adopted the HIVMA and AAHIVM recommendations for identifying HIV experts, while other states, including Arizona, have developed their own definition using similar criteria [40, 41].

Caseloads and appointment times vary greatly according to provider expertise, disease severity, and comorbidities. Clinic staffing levels and available resources also affect the number of patients that providers can effectively manage. Evolving productivity standards that support quality care by HIV clinicians should reflect the complexity and intensity of HIV care and allow adequate time to monitor and manage the patient's HIV treatment and primary care needs and provide oversight of comorbidity management.

### Access to an HIV Expert

The specialized expertise required of HIV clinicians contributes to a growing shortage of HIV medical providers and necessitates models for managing HIV care that can be adapted to the resources available in a community [42]. Under the Ryan White care model, HIV-infected patients typically have a medical provider who manages their HIV and primary care or an on-site medical team that includes an HIV expert who comanages patients with a primary care provider.

For healthier patients with less intensive medical and social service needs, a comanagement model in which a primary care provider has an ongoing consultative relationship with an HIV expert is also effective, particularly when the provider relationship is established at the time of the patient's HIV diagnosis. In this model, the patient has a primary care provider who consults with the HIV expert. The HIV expert manages the patient's HIV treatment through regular visits, typically at intervals of 3 to 6 months.

In settings with a dearth of HIV experts, a primary care provider may manage the ongoing care of the patient, with the HIV expert serving as an ongoing consultant via teleconference or telemedicine [43].

Regardless of the role of the HIV expert, the patient and medical provider relationship has proven to be central to effective primary care and chronic disease management [44, 45]. An ongoing and consistent relationship between patient and provider establishes open communication and trust. HIV patients who trust their medical providers have better medication adherence rates and are more likely to accept treatment recommendations [46–48].

### Quality Improvement

Quality improvement is an integral component of the HIV care model and a requirement of Ryan White funding [34]. Other integrated health systems have identified the value of such efforts [13, 49]. Programs collect quality and outcomes measures and utilize the data to evaluate and monitor clinical processes and

**Table 1. HIV Prevention and Treatment Guidelines and Recommendations**

Federal HIV-related guidelines and recommendations, including date of implementation <sup>a</sup>
Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents—10 January 2011
Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection—16 August 2010
Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States—24 May 2010
MMWR: Updated US Public Health Service Guidelines for the Management of Occupational Exposures to HIV and Recommendations for Postexposure Prophylaxis—30 September 2005
MMWR: Antiretroviral Postexposure Prophylaxis After Sexual, Injection-Drug Use, or Other Nonoccupational Exposure to HIV in the United States—21 January 2005
Guidelines for Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents—10 April 2009
MMWR: Guidelines for the Prevention and Treatment of Opportunistic Infections Among HIV-Exposed and HIV-Infected Children—4 September 2009
Incorporating HIV Prevention Into the Medical Care of Persons Living With HIV—18 July 2003
MMWR: Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings—22 September 2006
Guidelines Developed by the HIV Medicine Association of the Infectious Diseases Society of America <sup>b</sup>
Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: 2009 Update by the HIV Medicine Association of the Infectious Diseases Society of America <sup>c</sup>
Guidelines for the Management of Chronic Kidney Disease in HIV-Infected Patients: Recommendations of the HIV Medicine Association of the Infectious Diseases Society of America <sup>d</sup>
Guidelines for the Evaluation and Management of Dyslipidemia in Human Immunodeficiency Virus (HIV)-Infected Adults Receiving Antiretroviral Therapy <sup>e</sup>
Guidelines Developed by the International Antiviral Society-USA <sup>f</sup> Antiretroviral Treatment of Adult HIV Infection <sup>g</sup>

Abbreviations: HIV, human immunodeficiency virus; MMWR, Morbidity and Mortality Weekly Report.

<sup>a</sup> Available at <http://www.aidsinfo.nih.gov/Guidelines/Default.aspx>.

<sup>b</sup> Available at <http://www.hivma.org>.

<sup>c</sup> Clinical Infectious Diseases 2009; 49:651–81.

<sup>d</sup> Clinical Infectious Diseases 2005; 40:1559–85.

<sup>e</sup> Clinical Infectious Diseases 2003; 37:613–27.

<sup>f</sup> Available at <http://www.iasusa.org/guidelines/>.

<sup>g</sup> JAMA 2010; 304:321–33.

patient outcomes and to effectively manage limited program resources. Prevention, care, and treatment guidelines developed by the US Department of Health and Human Services and professional associations inform the scope and content of HIV provider practices (Table 1). Corresponding quality measures are employed to evaluate provider and practice adherence to standards of HIV care. Evaluations utilizing these measures are performed by the practice itself (internal quality management) and by funding agencies (external quality assurance) to ensure

**Table 2. HIV Quality Measures for Adults With an HIV Diagnosis**

Measure	Recommended national measure (HIVMA/HRSA/NCQA) <sup>a</sup>	2011 Medicare PQRS number <sup>b</sup>	NQF number <sup>c</sup>	HHS-proposed initial core set of health quality measures for Medicaid-eligible adults	HRSA/HAB HIV core clinical performance measures <sup>d</sup>
Retention in care	✓	...	0403	✓	✓
CD4 cell count	✓	159	0404	...	✓
Gonorrhea/chlamydia screening	✓	205	0409	...	✓
Syphilis screening	✓	208	0410	...	✓
Injection drug use screening	✓	207	0415	...	Substance use screening
High-risk sex screening	✓	206	0413	...	HIV risk counseling
Tuberculosis screening	✓	...	0408	...	✓
Hepatitis B screening	✓	...	0411	...	✓
Hepatitis C screening	✓	...	0414	...	✓
Influenza immunization	✓	...	0522	...	✓
Pneumococcal immunization	✓	...	0525	...	✓
Hepatitis B vaccination order	✓	...	0412	...	✓
Hepatitis B vaccination completed	✓	...	...	...	...
PCP prophylaxis	✓	160	0405	...	✓
Adolescents/adults prescribed ART	✓	161	0406	...	✓
Achieving maximal viral control (system level)	✓	...	...	...	...
Achieving maximal viral control (provider level)	✓	162	0407	...	...

Abbreviations: ART, antiretroviral therapy; HAB, HIV/AIDS Bureau; HHS, US Department of Health and Human Services; HIV, human immunodeficiency virus; HIVMA, HIV Medicine Association; HRSA, Health Resources and Services Administration; NCQA, National Committee for Quality Assurance; NQF, National Quality Forum; PCP, *Pneumocystis pneumonia*; PQRS, Physician Quality Reporting System.

<sup>a</sup> Horberg et al, Development of National and Multiagency HIV Care Quality Measures, *CID* 2010; 51:732–38.

<sup>b</sup> Measure included and assigned a number in CMS' 2011 Physician Quality Reporting System Individual Quality Measures, [http://www.cms.gov/PQRI/15\\_MeasuresCodes.asp](http://www.cms.gov/PQRI/15_MeasuresCodes.asp).

<sup>c</sup> National Quality Forum—endorsed standards can be accessed at: [http://www.qualityforum.org/Measures\\_List.aspx](http://www.qualityforum.org/Measures_List.aspx).

<sup>d</sup> Health Resources and Services Administration. HIV/AIDS Bureau. HIV Performance Measures, <http://hab.hrsa.gov/deliverhivaidscore/habperformmeasures.html>.

that patients are offered a uniform standard of care, regardless of location. This is particularly important in areas where HIV expertise may be lacking. In these areas, quality measurement can support workforce development by enhancing HIV knowledge and expertise among willing but inexperienced providers.

Rapid advances in HIV medicine make quality management and clinical practice tools, such as practice guidelines, critical to supporting and evaluating implementation of the latest standards of care. HIV-related quality measures developed by a consortium with the National Committee for Quality Assurance have been endorsed by the National Quality Forum and incorporated into Medicare's Physician Quality Reporting System (PQRS) [50]. Adoption of uniform measures across federal programs and by private insurers is important when evaluating and improving HIV care outcomes, regardless of insurance status or funding source (Table 2).

The HIVQual program developed by the New York AIDS Institute and the HIV/AIDS Bureau has assisted Ryan White–funded clinics with building sophisticated quality management systems. Participating programs use quality improvement and performance measures to improve their delivery of HIV care [51].

The PQRS, developed by the Centers for Medicare and Medicaid Services (CMS), provides incentive payments to providers for reporting on certain HIV-related quality measures. Reporting of HIV measures is currently limited to registries; this creates administrative barriers to participation for some programs, limiting the potential for the PQRS to improve HIV care [52].

### Electronic Health Records

EHRs are a key component of effective integrated care and medical home models. Although HIV programs are at varying levels of EHR implementation, HIV care programs, including many funded by the Ryan White program, have been leaders in using EHRs and/or electronic data collection to support quality improvement programs and to meet data reporting requirements. Many commercial products can meet these needs, and some health care systems and clinics have developed their own (examples include the VA and the University of Alabama at Birmingham [UAB] 1917 Clinic). A majority of Ryan White–funded medical programs utilize CAREWare, software developed by the HIV/AIDS Bureau in 2000 that is used to monitor clinical and supportive care (<http://hab.hrsa.gov/careware/>).



The Medicare and Medicaid EHR Incentive Programs provide financial incentives for providers to adopt and use EHRs and require providers to report on CMS-identified quality measures. HIV-specific measures were not included in stage 1 of the clinical quality measures. The addition of HIV measures during the next phase will be important to improve the delivery of care, align HIV program expectations across federal agencies, and monitor progress toward the goals of the NHAS [53].

### Sustainability

Financial viability is a component of effective HIV care delivery and is important to supporting access to expert HIV providers and programs. The financial operating requirements for the delivery of effective HIV care are complex, with many programs relying on institutional support to cover salaries, administrative infrastructure, rent, and other operating costs. However, in the current environment, models of care with costs that exceed benefits to the institutions are no longer sustainable.

Effective payment systems and methodologies are grounded in the cost of care, adjusted according to disease severity, and take into account nonclinical costs associated with chronic disease management, such as care coordination, quality monitoring and evaluation, and EHR adoption. With a few exceptions, most state Medicaid programs fall short in supporting complex, comprehensive HIV care. The new Medicaid health home benefit, for which HIV disease is identified as an eligible condition, provides an important opportunity for states to support this level of care [54]. The movement toward health home or medical home care provides an opportunity to transform the delivery of chronic care if supported through innovative and reasonable provider payment mechanisms.

### Fee-for-Service

The Medicaid and Medicare programs cover 40% and 20%, respectively, of people with HIV in care [6]. The inadequacy of payment rates under both programs contributes to health-related disparities in access and outcomes [55–57]. Medicaid rates average 66% of Medicare payment rates for primary care services, yet even Medicare rates fall short of supporting the true cost of care. In a study conducted by the 1917 Clinic at UAB, Medicare payments for physician services for patients with HIV disease averaged \$359 per year, with a range of \$285 to \$533 per patient per year, depending on disease severity [58]. The annual payment covers 18% of the \$1959 in per-patient medical provider costs incurred by the UAB 1917 Clinic for managing the patient's primary and HIV care needs (James Raper, DSN, CRNP, JD, personal communication, January 2011).

### Managed Care Capitation Rates

Under managed care, adequate monthly capitation rates are grounded in the cost of care and are risk-adjusted according to disease severity to ensure that quality and outcomes are not compromised due to cost [59]. A few states have developed

**Table 3. Maryland Medicaid Monthly Capitation Rates, 1 January 2011–31 December 2011**

	City of Baltimore	Rest of state
Disabled persons with AIDS	\$3030.41	\$2135.18
Disabled persons with HIV	\$1609.69	\$1609.69
Families and children with HIV	\$612.79	\$612.79

Source: Maryland Office of the Secretary of State. COMAR (codification number 10.09.65.19). Available at: <http://www.dsd.state.md.us/comar/>.

Abbreviation: HIV, human immunodeficiency virus.

payment mechanisms under Medicaid managed care to support HIV care. For example, the Maryland Medicaid program pays special capitation rates for Medicaid beneficiaries with HIV and AIDS that are adjusted for geography and hepatitis C status. Services with unpredictable costs are excluded and paid on a fee-for-service basis, including HIV antiretroviral agents, viral load, and HIV drug resistance testing (Table 3). In 2003, the New York State Department of Health's AIDS Institute established 3 managed care plans, referred to as HIV Special Needs Plans (SNPs), in New York City for Medicaid beneficiaries with HIV disease [60]. SNPs are paid capitation rates that exclude all pharmaceuticals, including antiretroviral medications; the rates are based on the enrollee's age and receipt of supplemental security income (Table 4). Beginning in October 2011, New York state plans to incorporate pharmaceuticals and other services previously paid on a fee-for-service basis into the managed care benefit package for HIV SNPs and other Medicaid managed care plans and to adjust the capitation rates accordingly.

### Public Health Funding

Appropriated by the federal government with contributions from state governments, Ryan White funding has allowed for the development of a robust system of care for people with HIV who are uninsured (nearly 30% of those diagnosed and living with HIV) or underinsured and at serious risk for going untreated in the absence of Ryan White-funded services [61]. Given the inadequacies of third-party coverage and payments, Ryan White

**Table 4. New York HIV Medicaid Managed Care Monthly Capitation Rates, March 2010–April 2011<sup>a</sup>**

Medicaid Eligibility Category	Monthly Capitation Rate
TANF adult	\$1136.37
TANF child <sup>b</sup>	\$672.82
SSI adult	\$1746.59
SSI child <sup>b</sup>	\$936.90

Source: New York State Department of Health AIDS Institute, August 2011. Abbreviations: HIV, human immunodeficiency virus; SSI, supplemental security income; TANF, temporary assistance for needy families.

<sup>a</sup> These rates will be adjusted in October 2011 to reflect costs for services such as pharmaceuticals that were previously paid on a fee-for-service basis because these services will be incorporated into the managed care benefit package.

<sup>b</sup> Under 21 years of age.

funding will remain vital to ensuring access to HIV care and treatment for individuals who remain uninsured or are underinsured under the ACA.

## CONCLUSION

The HIV care model that incorporates the best aspects of the medical home model and contributes to our remarkable success in treating HIV disease should be promoted and enhanced with national health care reform. Further evaluation of this HIV care model and its impact on patient outcomes and cost effectiveness is warranted to inform the development of financing and delivery systems that improve HIV care and care for other complex, chronic conditions. The ACA, steered by the NHAS, offers great promise for turning the tide of the HIV epidemic if it builds on the remarkable delivery and care programs developed by the Ryan White program and other HIV providers. However, Medicaid and Medicare payment reform for complex care management along with continuation of the public health funding available through the Ryan White program will be critical to maintaining the HIV care model. This reform and continued funding will also make it possible to improve outcomes for people with HIV and prevent HIV infection through effective HIV care. Weakening of this model, with fragmentation of care or a decline in essential services, will not only result in adverse consequences for HIV-infected patients but will also increase preexisting disparities in health outcomes and HIV transmission within at-risk communities, ultimately increasing the burden of disease and the cost of HIV care.

## Notes

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